

Spring 5-22-1978

# Morbidity and Help-Seeking Behavior in the Family Members of the Terminally Ill

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MORBIDITY AND HELP-SEEKING BEHAVIOR  
IN THE  
FAMILY MEMBERS OF THE TERMINALLY ILL

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(B.S., Massachusetts Institute of Technology)

A Thesis

Submitted to the Yale University School of Medicine  
in Partial Fulfillment of the Requirements for the Degree of

Doctor of Medicine

May 22, 1978

## ACKNOWLEDGMENTS

I wish to express my appreciation to the following people who generously offered their help and guidance:

Dr. Adrian Ostfeld, for patience and perspective on this very broad, interdisciplinary field of research.

Dr. Selby Jacobs, Dr. Andrew Slaby, and Chaplain David Duncombe, for help in shaping the project and encouragement at critical times.

The staff of Hospice, who helped to make the testing of the questionnaire a reality; in particular, Dr. Sylvia Lack, Dr. Samuel Thier, and Mrs. Kay McCarthy.

I would also like to thank my close friend Nancy Motola, whose encouragement and moral support sustained me through the work of this project.

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## Introduction

My interest in this area of research started two summers ago. At that time I was a student chaplain at Yale New Haven Hospital. While that may seem an unusual role for a medical student, it then seemed the solution to a dilemma that existed in my own mind. Balancing sensitivity to patient care in one hand and technical medical knowledge in the other was for me a difficult problem. The role of student chaplain offered an opportunity to explore the former area without obligation in the latter. The result was an intense exposure to the psychological and spiritual aspects of medical care.

There were several occasions that summer when problems of a potentially medical nature arose, which, however, fell squarely on my shoulders. These involved family members of the hospitalized patients. In several cases, particularly when the illness seemed catastrophic and fatal, the health of close family members seemed adversely affected. I offer two examples.

### Case I

Mr. P., a 59 year old man, suffered a massive heart attack and stroke. When I first had contact with him he had been hospitalized for one month and had a very dense motor aphasia. His level of consciousness fluctuated so that sometimes he seemed alert and responsive, while at other times he appeared quite obtunded, unreachable, and withdrawn. He had considerable difficulty swallowing and required nasogastric feedings. As a result of impaired gag reflex, he developed aspiration pneumonia frequently and required frequent regimens of antibiotics.

Mrs. P., 55 years old, visited him once or twice per week. She was a very temperamental, moody person, at times being very pleasant, at others spiteful, vindictive, and manipulative. Most of her anger was aimed towards the medical and nursing staff, whom she blamed for setbacks in her husband's illness. Her anger became particularly severe on several occasions when it was felt that Mr. P. might die from sepsis. As the medical staff approached her, she would drive them away with accusations. She hovered over her husband with inappropriate protectiveness, almost as if to keep staff away from him.

More aggravating and exasperating to the staff were her psychosomatic and psychiatric complaints. She had had chronic low back pain, which she complained about incessantly, particularly using it as an excuse why she couldn't visit her husband more frequently. Most frightening were her repeated threats of suicide, should her husband die. She also expressed homicidal ideas relating to her elderly, totally dependent father whom she cared for, should Mr. P. die.

She had been under psychiatric care in the distant past, but was no longer. The suggestion had been made that she seek psychiatric help, or at least that she seek medical help for her back problem, but she adamantly refused.

As chaplain on the floor, I visited her whenever she came to the hospital. She seemed to respond to me better than to other staff, probably because as a chaplain I could not be held accountable in her eyes for her husband's medical demise. Without her hostility present between us, we were able to establish a good rapport. She frequently expressed anguish about her husband, crying profusely about both his condition and her own suffering. Sometimes in the next breath, however,

she said, "I don't believe them, I know he's going to get well again. How can the doctors say that he won't?" Many times she said to me, "I don't know what I'd do without him. I don't know how I'd live. If he dies I'd kill myself . . ."

Though she was an infrequent churchgoer, she described herself as fervently religious, having absolute faith in God that her husband would get better. As chaplain I tried to explore some of the inconsistencies of her rather rigid religious attitudes and relate them to the difficult situation. At best, we achieved only temporary clarity and relief of her anxieties. A new complaint, confusion, or threat of self-destruction always emerged soon after.

Mrs. P. was clearly someone who was having trouble coping with the stressful, demanding situation of her husband's illness.

## Case II

Mrs. G. was a 60 year old Italian woman who has been hospitalized electively for routine workup of a medical disorder. About one week into her hospital course she had a cardiac arrest while in her private bathroom and was found unresponsive about five minutes later. She was successfully resuscitated and transferred to the coronary care unit where I was chaplain. After one week there, she began to regain consciousness, but only to a level of severe obtundation.

She spent about three weeks total in the CCU. During the first week her entire family of husband, six sons, daughter-in-law, sister, and cousin set up a 24 hour vigil in the visitors' waiting room. By the third day all had reached a point of severe exhaustion. Only with considerable difficulty, though, were they convinced to sit in shifts,

leaving others able to go home and rest.

Most problematic was Mrs. G.'s husband, who refused to leave his wife's side. He himself had had a cardiac condition. With his wife's sudden catastrophe, he started to experience anginal chest pains. He mentioned nothing of this to his family or to staff. It was only after someone found him in frank discomfort that he was confronted with his own illness and convinced that he, too, needed rest and close medical consultation for his own needs.

From these and other similar cases, I was left with several questions: why did these patients' families, spouses in particular, have such a difficult and unhealthy reaction to the illness? Why didn't they seek help for their troubles? Is this a common phenomenon?

The following fall and spring, while a third year medical student, I explored the possibility of doing thesis research at Hospice, an organization that is dedicated to caring for the special problems of the terminally ill. The Director of Research at the time, Robert Buckingham, pointed out evidence of ill health in a substantial proportion of close family members who take major responsibilities for care of the patient in the home. He suggested that little had been done to explore health and disease in the family members of terminally ill adults. So, I was launched into this project.

At first, I hoped to develop self-report questionnaires which would be administered to a large number of subjects and matched controls. Discussing research on bereavement, Parkes (1972, p. 119) has pointed out the need for both detailed information from in-depth interviews of small numbers of subjects and statistical analysis of large population samples. It is my belief that the same is true for research in the family members

of the terminally ill. Ideally, both kinds of research should complement each other. As will be pointed out below, there have been considerable analyses of empirical observations, but few statistical studies.

As plans for the project developed, however, Dr. Ostfeld pointed out the impracticality of a rigorously controlled study in this field, given my time and energy constraints. Instead, I have developed a questionnaire and administered it to a limited number of Hospice patients' family members, with the intention of testing it as fully as possible. The questionnaire is designed to identify and characterize those persons with significant unmet health needs. It is hoped that from this study a new and better questionnaire can be developed that could be administered to a much larger group in future research.

Before beginning the literature review and presentation of the questionnaire, it is necessary to define some of the terms used.

Grief - The characteristic response to loss of a valued object (Engel, 1961). This usually, but not always, involves an intense, personally experienced emotional reaction.

Bereavement - The act of deprivation caused by the death of a person. The period of bereavement, referred to in some of the literature, is the time period that immediately follows bereavement.

Object Loss - The act of being deprived or of being without something one has had (Peretz, 1970b).

Mourning - The social dimension of grief and bereavement. This encompasses the social role taught, elicited, and reinforced by society (Jacobs and Ostfeld, 1977). When the reaction to loss affects both the personal and social realms, grief and mourning can be used interchangeably.

Terminal Illness - Illness which under most circumstances will end in death at an earlier time than what would otherwise be expected.

Anticipatory grief - the grief response which occurs prior to the time of bereavement or object loss. It is dependent upon an awareness on some level of the fact of impending loss.

Illness Behavior - Any activity, undertaken by a person who feels ill, to define the state of his health and to discover a suitable remedy. The principal activities here are complaining and seeking consultation from relatives, friends, and from those trained in matters of health (Kasl and Cobb, 1966a).

Sick Role Behavior - The activity, undertaken by those who consider themselves ill, for the purpose of getting well. It includes receiving treatment from appropriate therapists, generally involves a whole range of dependent behaviors, and leads to some degree of neglect of the person's unusual duties (Kasl and Cobb, 1966b).

Help-seeking Behavior - Any activity, undertaken by those who consider themselves to be in need, to approach or make contact with another person who is believed to be able to define, correct, or fulfill that need.

Dying Role - The social role taken by a person for whom nothing more can be done to restore health or prolong life in a manner that is acceptable to him and that maintains his dignity, well-being, and humanity (Siegler and Osmond, 1976).



## I. Review of the Literature

### I.A. The Family Member's Reaction to the Dying Patient: Directly Applicable Literature.

The original data that attracted my interest to this area comes from a recently completed but as yet unpublished study of Hospice patients and their family members and their primary care persons. The primary care person (PCP) is the person in the house, almost always a close family member, who is responsible for day to day care of the patient in the home. In about two thirds of cases this is the spouse. Preliminary data from self-report questionnaires (Buckingham, 1977) showed that 36% of PCP's considered that they had fair or poor health. In addition, anxiety in PCP's was high, in some cases higher than that of the terminally ill patient. The study was designed to explore social adjustment and psychological symptomatology but did not attempt to characterize physical health further.

Approaching the field of interest of this study to find published data, however, one finds a dearth of quantified information.

Some of the available data comes from a study by Ward (1974), who studied sociologic characteristics of 279 terminally ill cancer patients, their families, and the care they received in Sheffield, England. Ward identified one person in each family who served as the "chief carer," similar to the PCP. To assess their health, she contacted local general practitioners for their opinions. Of 200 subjects so evaluated, 40% were felt to have fair or poor physical health and 46% fair or poor morale. Some general practitioners did not know or were reluctant to give such information, particularly if the patient had been hospitalized soon after becoming ill. Since a slightly higher percentage of caregivers

with fair or poor health than good health had spouses that died in the hospital (64% vs. 57%), the figure of 40% may be an underestimate. In any case, it represents a substantial prevalence of ill health in the population, supporting Buckingham's preliminary data.

Depression and other symptoms occurring during the terminal illness have been analyzed retrospectively by Clayton and associates (1968,1973). In the 1968 study, 40 recently bereaved individuals were interviewed about symptoms, use of medication, and use of alcohol. As an example of the chronology of a symptom, they use depressed mood. Of 33 subjects who had never been depressed before, 14 (42%) admitted to having depressed mood during the illness. Another 2 out of 6 subjects with prior history of depressed mood also had depressed mood at this time. Overall, 16 out of 39 subjects (41%) admitted to depressed mood during the terminal illness. Analyzing similar data for alcohol consumption, they note that all who used alcohol after death (55% of subjects) had done so before the terminal illness. Several stopped during the illness while several others, mostly heavy drinkers, increased their consumption during the illness.

Unfortunately, the presentation does not permit discerning this information about other symptoms or medication use. Subjects with symptoms starting during the terminal illness are lumped together with subjects whose symptoms started before.

In the 1973 study, Clayton and associates analyzed symptomatology occurring during the terminal illness, by length of illness. Symptoms and use of medication were determined retrospectively one month following bereavement. 81 subjects with illnesses longer than five days were examined. Only age and irritability significantly differentiated between

the long illness group (more than six months) and the short illness group (less than six months), and those were interrelated (Clayton, et.al., 1971). Therefore, no substantial differences in symptomatology existed between the two groups. Symptoms and medication use are presented for the 81 subjects as a whole in Table I. The high incidence of depressed mood, sleep disturbance, and crying is notable. A depressive symptom complex, based on the diagnostic criteria of Feighner and associates (1972) was present in 19 (23%) of the subjects prior to bereavement. Clayton and associates equate this symptom complex with the presence of anticipatory grief. Whether or not that is true remains to be demonstrated. In any case, for both this and the 1968 study, the retrospective nature of the data collection, obtained at a time when many, if not most subjects were in the midst of acute grief, limits the reliability of the results.

Research in the field of nursing has produced several studies that examine the interaction of the professional staff with the dying patient and his family. Two of these offer specific information about the needs of the family member.

Hampe (1975) interviewed 27 spouses of terminally ill patients at a midwestern medical center, during the terminal illness. The age range was 20 to 71 years, and most subjects were over 50 years old (63%), male (59%), upper-lower social class (82%) married more than 20 years (74%), Protestant (86%), irregular church goers (67%), and had children (74%). From a review of the literature, she defined eight basic areas of need spouses could be expected to have. Interviews were structured to focus on those needs, to elicit whether or not the needs had been met. The specific needs, the number of subjects identifying each as important, and the percentage of those subjects with the need unmet appear

Table ISymptoms During Terminal Illness

(Source: Clayton and Associates, 1973)

Symptoms <sup>1</sup>	Percent of subjects admitting to having symptom during the terminal illness N = 81*
Depressed mood	68
Sleep disturbance	72
Crying	62
Anorexia	46
Weight loss	46
Difficulty concentrating	26
Poor memory	35
Loss of interest	30
Anxiety attack	10
Irritability	20
Fatigue	46
Feeling worthless	6
Feeling burden	4
Feeling guilty	6
Feeling hopeless	11
Wish to be dead	5
Thoughts of suicide	0
Fear of losing mind	0
Depressive symptom complex	23
Use of medicine:	
Sleeping	20
Tranquilizers	27

<sup>1</sup> Elicited retrospectively one month after bereavement.

\* Although it is not mentioned in their paper, the percentages as calculated in their tables suggest variation in N.

in Table II. In general, aspects of all eight needs were identified as important by 25 (93%) of the 27 subjects. The high percentage of the unmet need for assurance of the patient's emotional comfort may be misleading; if the need were being met adequately, it is possible that the subject would not have acknowledged it as an important need at all.

It should be noted that the identification of needs as important and the incidence of unmet needs may be related to the population and setting of the investigation. In other settings, particularly the home or a community hospital, some of these needs might become more or less important and be met more or less frequently. In the home, this would depend in large part on the quality and sensitivity of home care offered. The diversity of social and psychological behavior occurring after death in different cultures has been described (Krupp and Kliegfeld, 1962; Rosenblatt and Associates, 1972). In the presence of a different social structure and different attitudes towards death, grief, terminal illness, and the role of the "professional" healer, the needs of the spouse of the dying patient might be expected to differ from those presented here.

Verification of the importance of some of Hampe's needs comes from another study. Freihofer and Felton (1976) studied 25 pairs of terminally ill patients and close family members to determine nursing behaviors which offer the greatest comfort, support, and ease of suffering. The ages of the family members ranged from 22 to 77. Of the family members, 11 (44%) were male, 20 (80%) were spouses to the patient, and 19 (76%) were Protestant. The method of investigation involved giving each family member 88 categorized cards describing possible interactive behaviors. The subjects then sorted out the cards, ordering them from the

Table II

Needs of the Spouses of the Terminally Ill  
in the Hospital Setting

(Source: Hampe, 1975)

Need	Number of subjects identifying need as important N	Percentage perceiving need as unmet % of N
1. Need to be with the dying person	27	37
2. Need to be helpful to the dying person	25	0
3. Need for assurance of comfort of the dying person:		
(a) Physical	27	67
(b) Emotional	16	88
4. Need to be informed of spouse's condition	27	15
5. Need to be informed of impending death	27	7
6. Need to ventilate emotions	27	48
7. Need for comfort and support of family members	27	22
8. Need for acceptance, support, and comfort from health professionals	26	58

most desired behavior to the least desired behavior. The most desired behaviors chosen by subjects related to keeping the patient comfortable and calm, while the least desired behaviors related to direct emotional support of the family member. Specific least desired behaviors were: encouraging the subject to cry, holding his/her hand, and crying with him/her. There was high correlation in rankings between Protestants and Catholics, and between men and women, although specific rankings of individual behavior items differed among these groups.

The most desired behaviors correspond to the first five of Hampe's eight needs of the patient's spouse in the hospital setting. Least desired behaviors correspond to the other three. The study does not really negate the importance of those needs, but it does suggest that in the hierarchy of needs facing the family member of the terminally ill, needs for support and emotional ventilation are seen as less important. Since the ordering of the cards was subjective, it is possible that family members would have assigned lesser desirability to some very important needs they didn't want to admit they had. The evaluation of such needs as unimportant is at variance with most empirical studies in Thanatology.

A vast amount of literature has explored the reactions of parents to terminal illness in their children. Several investigators have explored this quantitatively (Hamburg and Adams, 1967; Meyerowitz and Kaplan, 1967). Though potentially directly comparable to the situation of terminal illness in adults, the dynamics of interaction have many differences. For that reason, these studies will not be analyzed extensively in this paper.

Many others have written from an empirical perspective. Kubler-Ross

(1969) and Heimlich and Kutscher (1970) and Fulton and Fulton (1972), to mention a few, have commented on various aspects of the family's reaction to terminal illness. The most thorough and systematic of these analyses is written by Maddison and Raphael (1972). Based largely on empirical observation and extensive application of aspects of general community psychiatry, their discussion explores reactions of individual family members, the family unit as a whole, and the family with the community. Because of its direct applicability, I will summarize it now. In addition, Nighswonger (1974) has described the family's interaction with the community, professional staff, and patient, and I will incorporate some of his concepts into the discussion.

Maddison and Raphael (1972) note that the psychological reaction of the individual family member can take many forms and is affected by many variables. Three basic issues form niduses around which conflicts can mobilize: dependency, aggression, and sexuality. A wide range of psychological defenses can be enlisted to cope with these conflicts. If these fail, pathologic sequellae may result.

If the family member has been excessively dependent upon the patient, difficulties may arise. Over the course of the illness, the family member will have to give up his/her dependent relationship to the patient. Inability to do so can lead to identification phenomena involving the patient's illness or symptomatology, depression, or other psychiatric or somatic illness, or reactive pseudoindpendence. The last of these responses developed in reaction to the unresolved dependency needs may be particularly fragile, leaving the person precariously balanced between awareness and denial of the needs.

With respect to aggression, family members may feel resentful



from the burden they must bear. If the patient has been manipulative and controlling, the illness may excite longstanding unexpressed hostile and revengeful fantasies. This is particularly true in illnesses that are self-inflicted through bad habits, lack of cooperation, or postponement of treatment. Reactions involving such hostile thoughts and fantasies may take the form of overt hostile expression, displacement of anger and resentment onto other objects--frequently hospital personnel and extended family, internalization with resulting development of depression, and overcompensation with resulting overprotective concern for the patient. All of these can lead to guilt and self-reproach.

Sexual conflict can occur when the patient is the object of sexual desires and is lost or changed, particularly after mutilating surgery or disease. Problematic reactions to this can take the form of sexual acting out or reactivation of sadomasochistic fantasies. A third and likely possible reaction related to these is extreme sexual repression and inhibition from guilt feelings associated with the acting-out behavior or fantasies.

The perception by the family member of the terminal illness as a crisis depends upon several factors. The change in the role the patient has held in the family is important. If the role has been an important one to the family unit, the family member will have more difficulty adapting to it. If involvement has been intense, the loss will be all the greater. Prior experience with similar losses can affect the family member's coping. If successful, such experience would tend to alleviate the crisis nature of the situation; if unsuccessful, it would tend to aggravate it. In general, prior successful coping with other types of stressors would tend to alleviate the crisis, while any history of unsuccessful coping would tend to do the reverse.

Reactions of the family group as a whole have characteristic patterns that can affect the individual members. Movement of the patient into the sick role or dying role may require significant changes in family dynamics. This can be very trying for family members, particularly if the patient has been the family leader or family scapegoat. Patterns of interaction may have to be substantially reconstituted. Roles may have to change, and new roles may have to be learned. Others will have to assume the responsibilities held by the patient. Financial problems at this time can become acute, particularly when members of the family have to change employment, quit, or retire to assume new obligations. As a result of these changes, certain resources available to the family may decrease drastically.

Adoption of sick-role behavior by the patient may mean that others have to relinquish it. How easily sick role behavior is accepted by the family depends in part on the age of the patient, intensity of involvement with others, and the length of illness. If the patient is young, involvement high, and the illness acute, the family may have considerable difficulty accepting the patient's movement into the sick role.

Communication patterns in the family may contribute to tension and strain. Some families react to terminal illness with avoidance and a conspiracy of silence. This can block realistic planning and the working through of anxieties. It can also detrimentally affect the patient's health. Overall, it is likely to add to guilt feelings present, which, in turn, can lead to further avoidance of the patient, in a vicious cycle. Communication patterns favoring denial of the seriousness of the illness will be more and more difficult to maintain as the patient deteriorates. Inflexibility of the communication channels in response to worsening

symptoms can cause strain. Ironically, the same may be true if there is an unexpected remission of the disease. The family may have to revert back to prior role patterns, which may be very difficult.

Hospitalization during the terminal illness usually benefits the family. Sometimes respite from the ongoing pressing needs of the dying will help the family regain its strength and equilibrium. However, if the family's coping has consisted of denial of dying, and if that has depended upon the patient not requiring hospitalization, then the family will have to alter its coping response and may suffer strain. In addition, when the patient wishes to remain at home but the family seeks hospitalization, the family may develop considerable guilt feelings.

The degree to which the situation is perceived by the family group as a crisis depends upon the basic integrity of the family unit, previous family experience coping with crises, and the presence of absence of concurrent crises. If the family structure is weakened, previous coping with stressors has been unsuccessful, and concurrent crises are abundant, there is stronger likelihood that the situation will be perceived as an additional crisis. Coping under such circumstances is likely to be maladaptive. Maladaptive family responses would affect individual members adversely, resulting in the development of psychophysiologic symptoms, psychosomatic disease, or disturbed behavior.

A third level of interaction affecting family members involves the community. Ethnic, cultural, religious, and social class characteristics all affect the relationship of the family and its members with society. Attitudes of the community towards the sick and dying may filter down to the family members; mores of social distance (Kalisch, 1966) may have to be overcome. The way the community is organized may

affect availability of resources and accessibility to them. On this level, friends, neighbors, or extended family may add considerably to the network of support available to the family. They may also cause strain, though, if they are unwanted or perceived by family members as being insufficiently supportive.

The community may also have expectations about how the family should act and behave during the terminal illness. Nighswonger (1974) has looked closely at how the community influences the family and family member's reactions. At one extreme, the community can refuse to support the family altogether, thus encouraging a reaction of panic to the crisis. It may reinforce denial and emotional responses based on denial. It may place taboos on overt expression of any feelings of distress and demand that individuals control emotions when in public. Finally, it can provide inadequate and irrelevant perspectives on life to rationalize the illness. All of these would tend to block communication of needs and feelings and would serve to maintain barriers between the patient and family. Conversely, if toleration of such feelings exists and resources are accessible to the family, then communication channels would tend to be more open.

The professional staff can facilitate this communication as well. Proper attention to the patient's illness and general comfort will allay considerable family tension. The availability of someone who can be sensitive to the family's emotional needs can be very helpful. Such a person can facilitate the family member's appropriate expression of anticipatory grief and acceptance of impending death. If that can be done, the grief processes of the patient and family may be synchronized, to the benefit of all.

The above studies indicate the presence of health problems in this population, the extent and importance of certain needs, and the sources of stress faced by the family members within the social system. In scope, however, the definitive results offered leave much to be explained. To understand some of the mechanisms underlying development of illness in this group it is necessary to examine related areas of knowledge. Terminal illness may involve significant loss with accompanying grief reaction; many investigations have linked general loss and reaction to loss with the development of illness. Several works also explore the morbidity associated with anticipatory reactions. Information about the sequelae of bereavement is also applicable, as many of the variables that affect reaction to bereavement may also affect anticipatory reactions prior to bereavement. The burden of caring for a chronically or terminally ill patient at home can be a major stress; several authors explore responses of family members to it. Since the patient shares so much of the same environmental and social factors as the family members, it would be useful to review some of the factors affecting the patient's reaction to impending death. All of these related areas are explored below in detail.

## I.B. Reaction to Loss.

### I.B. 1. Description of Grief and Association with Illness Susceptibility

Grief, the reaction to object loss, has been likened to a disease process. Engel (1961) described grief as having three relatively straightforward stages. There is an initial phase of shock and disbelief, during which there may be attempts to deny the loss and to protect against the utter shock of the loss. A second phase involves a developing awareness of the loss, which includes pain or sadness, guilt, shame, helplessness, or hopelessness, general depressed mood, crying, a sense of loss and emptiness, anorexia, and sleep disturbance. Sometimes somatic discomfort or pain occurs. There is loss of interest in work and other activities, impairment of work performance, and difficulty completing tasks. Finally, there is the third, often prolonged phase of recovery, during which the loss is overcome and a state of health and well being returns.

A component of the middle stage, well characterized by Parkes (1971, 1972, 1975b) in primarily young subjects or psychiatric patients, is the process of pining for the lost object. The individual has an urge to search for the lost object. There is restlessness and sometimes urges to aggressive action. In the case of bereavement of a loved person, identification phenomena may develop; the lost person is seen or felt as inside the grieving individual or nearby. Such phenomena are often associated with the presence of guilt feelings. There is yearning with "pangs of grief."

Like a disease, grief has an onset, course, and completion, a progression of symptomatology, and possible sequelae. Many other authors have noted the symptomatology of grief in diverse populations. Many uncontrolled qualitative and quantitative studies have demonstrated the

symptoms of grief following bereavement (Lindemann, 1944; Gorer, 1965, pp. 49-57; Clayton, et. al., 1968; Parkes, 1972, pp. 210-211). These have been corroborated in controlled studies (Maddison and Viola, 1968; Clayton and Associates, 1971; Parkes and Browne, 1972). Other works have described the occurrence of the grief process following other types of loss (Schoenberg and Associates, eds., 1970). As we shall see, the above processes are usually, but not always self-limited.

In terms of sequelae, object loss and the aspects of grief of depression, hopelessness, and helplessness have been associated with the development of prolonged, serious, and occasionally fatal somatic disease. Reviewing earlier literature, Carr and Schoenberg (1970) list many specific diseases linked to separation and depression, including: cancer, tuberculosis, ulcerative colitis, idiopathic glossitis, asthma, obesity, thyrotoxicosis, rheumatoid arthritis, congestive heart failure, leukemia, lymphoma, and diabetes mellitus. Other studies which we will now discuss, explore this phenomenon further.

Early psychosomatic literature attempted to link personality characteristics and psychological events to the development of disease. In an extensive review of this literature, LeShan (1959) studied these factors as they apply to development of cancer. The most consistently reported psychological factor found was loss of a major emotional relationship prior to the development of symptoms.

Schmale (1958) interviewed 42 inpatients admitted for a variety of medical problems. The sample was largely unselected, and only patients who were too sick to be interviewed or who were discharged quickly after admission were excluded. Schmale found that 29 (69%) had recently experienced actual, threatened, or symbolic object. For all but one of the

remaining, he was able to interpret the presence of some kind of loss from the interview material. In addition, 30 (71%) expressed feelings of helplessness and 10 (24%) expressed hopelessness during the interviews. He concluded that separation or loss in combination with helplessness or hopelessness is associated with the development of disease.

A problem with this study was the retrospective nature of both selection of subjects and interview content. To correct at least the first of these weaknesses, Schmale and Iker (1966) interviewed 40 women with abnormal pap smears, after admission for cervical biopsy to rule out malignancy. Based on the interviews, they made blind predictions as to which subjects would and would not have positive biopsies. Criteria for prediction of cancer included the presence of hopelessness in response to a life event prior to the first cervical smear, or a high potential for hopelessness. Their predictions were correct for 8 out of 14 who were biopsy positive and 23 out of 26 who were biopsy negative. Statistically this was significantly different from the null hypothesis, indicating the predictability of their criteria.

Hopelessness and potential for hopelessness are also important aspects of clinical depression. Several investigators have explored the relationships between depression and the development of disease prospectively.

Imboden, Canter, and Cluff (1961) administered the Cornell Medical Index (CMI) and several keys of the Minnesota Multiphasic Personality Inventory (MMPI) to 540 men and 60 women at Fort Detrick. During the subsequent 17 months 26 (4.3%) developed and reported symptoms of influenza. 14 of these recovered completely after several weeks while the remaining 12 were still symptomatic at followup evaluation. The test scores from



both groups were compared. It was found that the symptomatic group had significantly higher scores on the depression and morale-loss keys of the MMPI, suggesting a link between depressive personality tendencies and severity of illness. CMI scores for the symptomatic group were also higher, though, and as Thurlow (1967) suggests, the difference in outcome may have reflected a difference in the perception and reporting of symptoms.

Parens, McConville, and Kaplan (1966) analyzed factors associated with illness susceptibility in a group of 136 nursing students. Here the loss consisted of moving away from home. Those who had better adjustment to the separation had significantly lower illness frequency during the first eight months of separation than those with poor adjustment. There was no significant relationship between depression scores measured at 6 weeks after moving and illness frequency, but when high and low quartile scores for helplessness and hopelessness were analyzed, it was found that those in the high quartile tended to have high illness frequency and those in the low quartile tended to have low frequencies.

The same difficulties that apply to Imboden, Canter and Cluff (1961) also apply here. Did somatic illness actually develop more frequently in the group with high hopelessness/helplessness, or did the observed association result only from an increased tendency to be bothered by symptoms and an increased tendency to report them? Three prospective studies demonstrate more conclusively a connection between depression or depressive tendencies and survival.

In a prospective study of coronary heart disease, Lebovits and Associates (1967) administered the MMPI to 1990 men. The scores of 15 men who suffered myocardial infarction and died suddenly were compared to

the scores of myocardial infarction survivors and age- and education-matched controls. It was found that the nonsurvivors had higher scores than survivors on many scales. On the depression scale, the mean score for nonsurvivors was not only significantly higher but also substantially greater than that for survivors. Thus, sudden death was associated with high depression scores.

Stavraky and Associates (1968) administered a battery of personality and psychological tests to 204 patients with cervical, breast, and lung cancer at the beginning of their treatment, then examined length of survival 40-66 months later. 23 patients with the most favorable outcomes and 23 with the least favorable outcomes were compared to 46 stage-matched controls of average survival. The least favorable group differed little from the control group. On the other hand, a significantly greater proportion of the most favorable outcome group had a combination of strong, hostile drives without loss of emotional control.

Weissman and Worden (1975) looked at cancer survival in 35 terminally ill patients. To measure outcome, they used a "survival quotient," that is, the difference between actual and expected survival divided by the standard error of estimate of survival for that particular neoplasm and stage. From interviews with the subjects they found that longstanding alienation, depression, deprivation, and poor social relationships tended to correlate negatively with the survival quotient. Rising resentment and general absence of depressive affect correlated positively.

The first and third of these studies suggest a strong association between the presence of depression or depressive tendencies and poorer survival. The study by Stavraky and Associates indirectly supports this; the psychological profile of strong hostile drives without loss of emotional

control would seem to be the antithesis of the personality structure within which depression with hopelessness would occur.

### 1.B.2. The Conservation-Withdrawal Mechanism

To explain the associations between object loss, hopelessness, and illness susceptibility, Engel and his group at Rochester postulated the existence of a conservation-withdrawal mechanism (Engel, 1967). Like the "fight-flight" mechanism described by Cannon (1929) as a protective reaction to stress under certain conditions, this is a set of responses that serve to protect the organism under other conditions. It would tend to come into action, however, in situations where the active response of fight-flight no longer works. The mechanism tends to conserve energy, reduce activity, and diminish contact with the environment. In an infant or wounded animal, it would serve to protect from predators. In the process of this "protection," however, the organism undergoes a kind of cognitive and psychosocial dysfunction. This is very similar to the disorganization of the second phase of the grief reaction, and may be related to it.

The physiologic correlates of this response could predispose in the right condition to development of somatic derangement and disease. To prove such a relationship, though, is not so easy. Frederick (1977) has suggested that stimulation of the pituitary adrenal axis from stress (Seyle, 1956) following bereavement causes increased levels of circulating corticosteroids. These in turn cause suppression of immune mechanisms and predispose to the development of malignant or infectious disease. There are two studies that have begun to elucidate this phenomenon, and they both point to the fact that the process may be more complicated.

Hofer and Associates (1972) studied 40 parents of children dying of leukemia and found two basic "styles" of 17-hydroxycorticosteroid (17-OHCS) excretion that occurred. One subgroup with relatively low rates

of excretion prior to loss significantly increased their rates after bereavement. Another subgroup with high rates prior to loss decreased their rates after bereavement. Extensive structured interviews with members of these groups revealed that those with high rates following bereavement tended to have more active and intensive expression of grief and mourning than those with low rates. Several of the parents were followed daily during their children's illnesses. From continuous observations and frequent interviews, Mason (1975) noted an association between outward relinquishment of psychological defenses and increase in 17-OHCS excretion. Unfortunately, the small numbers of subjects and lack of controls limit inferences that can be drawn from this data.

Bartop and Associates (1977) investigated endocrinologic and immune function in 26 bereaved persons and matched nonbereaved controls. They found significant differences in T cell lymphocyte function between the two groups, particularly at six weeks following the loss. The T cells of the bereaved group had significantly reduced responses to mitogen stimulation. The numbers of T and B cells, antibody levels, and thyroid and pituitary hormone levels were not increased above controls. The authors conclude that bereavement is associated with significant depression of T cell lymphocyte function. Any other change in immune function, though, remains to be demonstrated.

Several authors have offered other explanations for the observed illness susceptibility associated with characteristics of the conservation-withdrawal reaction.

Haney (1977) suggests that adverse life events and the psychological depression and disorganization that so frequently accompanies them, can determine the extent to which a person perceives symptomatology

as threatening, attends to his body, and seeks appropriate help. In other words, it is the psychological process that determines whether the person will take proper care of himself and will respond appropriately to symptoms that develop.

Lipowski (1974) looks at the process from a different viewpoint. Stimuli from adverse events--or from ordinary daily life in this highly technological society--can reach a level of subjective experience overload for an individual. This in turn can cause excessive cortical arousal which may precipitate cognitive impairment, unpleasant feelings, and the development of psychological or somatic illness.

It is likely that illness susceptibility involves a combination of all of these factors. Ader (1977) proposes that, in the presence of potential pathogenic stimulation, conditions most conducive to the development of disease would include: (1) biologic disposition, (2) a personality structure so that some change in the psychosocial environment is perceived as "stressful," and (3) environmental change that the individual is unable to cope with. Until the latter of these conditions occurs, the organism can respond in a fight-flight manner, drawing upon its resources to cope with the "stressful" situation. When the organism is unable to cope with the change, for whatever reason, then the conservation-withdrawal mechanism may be initiated. This can serve to protect the organism in some circumstances. If so disposed, however, the organism may develop illness.

From the works of Engel (1961) and Parkes (1972) described in the previous section, it would appear that reaction to loss involves a spectrum of responses that dynamically change with time. At one end of the spectrum are the overt affective manifestations of grief and the active

searching for the lost object. At the other end are more inwardly directed processes, including depression, despair, and feelings of helplessness and hopelessness. The studies in these two sections link the latter group of processes to the development of illness, and point to the existence of the conservation-withdrawal reaction as a physiological mechanism that may be responsible for this. Jacobs (1978) has suggested that these processes may mediate some of the morbid and mortal sequelae of grief. This is logical, but has yet to be proven definitively. The questions of whether some persons are more susceptible than others to developing the conservation-withdrawal reaction, and why some persons but not others become ill remain to be answered.

### I.B. 3. The Ontological Meaning of Grief

Why should object loss evoke such a severe reaction? Why should the conservation withdrawal mechanism come into play following object loss? In this section I try to explore the connection between the two from a developmental point of view.

Bowlby (1969) has written about the response in young children to separation from the mother. He notes three basic phases of response of protest, despair, and detachment. In the protest phase the child is very physically active and cries. There is rejection of any alternative help and care offered. The child gives indication that mother is expected to return. Such active behavior on the part of the child would serve ontologically to help find the mother. This could be likened to the anxious searching and yearning that occurs in Parkes middle stage of grief. It is an organismic response which in the bereaved takes the form of searching for the lost person or reminders thereof. No amount of rationalization or cognition that the lost person is dead can mitigate the need to search.

Based on Bowlby's work, Parkes (1975b) has described the process of coming to terms with the fact of loss as one of realization, where the individual must repeatedly match the reality of the situations to his inner expectations. If there is disjunction between expectations and reality, then the expectations must be changed. If the change is small, it can be easily accommodated. If the change is large, as in bereavement of a close loved person, then the process can take place only by a slow, gradual, and painful set of matching processes.

In Bowlby's second phase of despair, less and less of the



anxious searching behavior is present. The child is still preoccupied with the missing mother, but there is increasing hopelessness. He becomes withdrawn, inactive, and very quiet, and makes few demands on the environment. Ontologically, such behavior would tend to protect from predators and other environmental hazards until the mother or some other adult protection reaches the child. It would also facilitate the child's focussing energies inward instead of outward, as that is where the bulk of work of coming to terms with separation has to occur.

In the bereaved, this could be likened to Engel's second phase of grief. The depression and hopelessness that may serve to facilitate the inner work in the child may do the same in the adult. Protection from the environment may involve temporary prevention of new relationships from developing until the work of grief is completed. On the somatic level, however, this response might not be so healthy for the adult, as we have seen. The child may be constructed so that when conservation-withdrawal comes into play, it is vital and protective. In the adult, it may facilitate the psychological work of grief, but in so doing may also predispose to the development of disease and ill health.

Bowlby's third phase is one of detachment. Here the child becomes more interested in his surroundings and accepts toys and care offered him. He is more sociable and interactive. On the other hand, if the mother visits, behavior characteristic of strong attachment and interest is absent. The child may hardly seem to know her. Although the behavior seems almost brutal on the child's part, should the mother never return, it does make possible new attachments. It is evidence

that the work of mourning in the child has taken place.

The same is basically true in the bereaved adult. Only after the work of grief has taken place can the individual invest himself in new relationships. Parkes (1975a) describes the process of psychosocial transition following bereavement as involving a major change in the "assumptive world model," which is the individual's set of views and expectations about the reality within which he/she lives. While minor perturbations in the model are easily accommodated, large changes are not. The change that occurs following bereavement renders a large part of the world model obsolete. A destructive process must then take place in which the obsolete aspects of the model are eventually cut down or diminished in meaning or eliminated totally from the model. Only in the space left over or freed up by this process is there room for learning of new assumptions and development of new relationships.

The obsolete parts, however, are quite tenacious, and not so easy for the person to let go of or destroy. It takes considerable work to begin to loosen their connections and their influences. Without the long and painful emotional work of grief, including perhaps a period in which the person's energies are turned totally inward, it is unlikely that this process would ever take place, or that new involvements would be possible.

#### I.B.4 Psychosocial Transitions: Theory and Application to the Reaction to Terminal Illness

From his observations with persons facing surgery and other stressful events, Janis (1958) formulated the concept of the "Work of Worrying." Before a major event, whether real or imaginary, people tend to anticipate, to worry. This serves the function of focussing attention on possible dangers and providing opportunities to plan accordingly. It allows the person to begin to change his view of the world. It makes it possible for people to react appropriately and not catastrophically when the anticipated event occurs.

When faced with the probability of death of a loved one, however, only so much of what may happen is generally anticipated. Many people questioned after bereavement report that they made no plans at all, even though they had been informed of impending death (Parkes, 1971; Silverman, 1974).

A potential reason for this is that the process of anticipation of the death of a loved one is quite painful. Many authors have likened it to a form of grief, so-called "anticipatory grief." Peretz (1970b) has suggested that in almost all cases where death is expected, the family will experience some form of anticipatory grief reaction. Manifestations can vary from quiet periods of sadness and tears to any or all symptoms of grief seen after bereavement. As death approaches, the reaction may accelerate and intensify (Aldrich, 1974).

In parallel with the outward manifestations of grief, the inner reaction of a change in the assumptive world model can be equally tumultuous. To begin to understand the family members' reaction to impending death it

is necessary to examine the possible ways the assumptive world model and its aspects can change in psychosocial transitions in general. Parkes (1975a) defines three possible changes to world models and their aspects.

The first change possible is total abandonment of aspects of the former assumptive model. This means, literally, forgetting that section of the past and present reality made up by those aspects. Circumstances favoring successful adaptation to such change include (a) relative unimportance of the part of the assumptive model, (b) full preparation of the person for the change, (c) wished for changes, and (d) presence of an attitude towards the world which enables it to be regarded as provisional.

The second type of change involves modification or partial retention of the former assumptive model. Parkes suggests that this is the usual circumstance following bereavement. Despite outer changes, aspects from the former model persist. Sometimes these can be helpful and other times unhelpful to adaptation. Important values of the lost person held dear by the bereaved may help to facilitate the transition. If such values are retained rigidly and inappropriately, they may hinder it. It is necessary to subject aspects of the world model to reality testing repeatedly. If this is not done, such aspects of the model will tend to persist.

The third and final type of psychosocial transition is encapsulation. Here the old world model is retained unchanged, alongside the new model. The prior assumptive model is perceived as more secure, fulfilling, and rewarding than the new model that threatens to replace it.

It is likely that prior to death the second type of psychosocial transition would take place. The assumptive world model of the family member that encompasses the terminally ill patient could be regarded as

having two basic subsets of assumptions. One set of assumptions centers around the fact that "the person is alive," while the other centers around the fact "the person will be alive." It should be noted that both of these are important and substantial; changing either involves a major transition. Prior to death, anticipation will likely involve changing the second subset but not the first. That is, the basic transition that will take place is from "the person will be alive" to "the person will not be alive." The transition from "the person is alive" to "the person is not alive" is likely not to take place.

The factors described as facilitating Parkes' first type of transition can be applied here to understand why this is true. Thorough preparation could come from gradual progressive deterioration and limitation of activity of the sick. It could also come from a gradual process of "disengagement" (Cumming and Henry, 1961) or distancing from the patient starting long before the terminal illness. Disengagement or distancing would also decrease the importance for survivors that the person will be alive and contribute to the ease of the transition. Wishing that "the person will not be alive" may cause problems, as the thought may be evaluated as having homicidal intention and may create guilt and self-reproach. It is possible, though, that where the illness causes prolonged severe strain acknowledged by all, such a wish might be more socially and psychologically acceptable. The presence of a strong attitude towards the world as provisional would virtually encompass the fact "the person will not be alive," making that part of the transition unnecessary.

Of these factors, thorough preparation, disengagement, and severe strain would also favor making the transition to "the person is not alive,"

but several facts would prevent this. First, while the person is still alive, the end result would be tantamount to psychological homicide or at least abandonment. Both of these would likely evoke very powerful feelings of guilt and self-reproach. Secondly, the processes of mourning by which psychosocial transitions can take place, would be likely not to occur. Mourning can occur only when there is a discrepancy between the assumptive world model as it is held inwardly and the situation as it really is; with respect to this subset, there would be no such difference. In terms of the phases of grief, one would expect not to see the anxious yearning, searching, and despair for the person not being alive, for the person is alive. The object of the search is present in reality. Without such grief processes, completion of the transition would be unlikely. (With respect to the transition to "the person will not be alive," searching behavior could, of course, occur. This would be manifested, for example, by the search for a doctor or healer who would say that the disease is curable and not fatal.)

The grief processes involved in coming to terms with both of these subsets of the assumptive model, however, are more complex. Working through both transitions prior to death--or at least a facsimile thereof--is not uncommon. In some individuals, the two subsets seem to have an interconnection; mourning for one loss automatically means mourning for the other. What results from this is near-total or total psychological disengagement from the patient, sometimes to the point of abandonment. This happens despite the presence of strong reactive guilt and self-reproach. It is as if the mechanism Bowlby (1969) describes in the child after long separation from the mother--the detachment from her and even lack of recognition of her--unconsciously comes into action.

Just as this process can further disrupt the relationship of mother and child, it also tends to create social and psychological problems in the adult. Lindemann (1944) described anticipatory grief in one woman who had mourned so thoroughly for her enlisted soldier husband, that upon his return she no longer felt close to him and sued for divorce. The "waiting vulture syndrome" of psychological estrangement and abandonment of the patient by staff and family who have worked through anticipatory grief has been described by Davidson (1975). Hamburg and Adams (1967) describe a similar set of reactions experienced by parents towards their fatally ill children. Fulton and Fulton (1972) describe another potential problem. Social expectations of active grieving can be very powerful at the time of death and soon after. If because of completion of the anticipatory processes there are no grief feelings to express, considerable hostility from family society, and health professionals may be evoked.

Thus, there are many problems that can arise if the family works through the loss prematurely. As the process nears completion, the ambivalent feelings that develop or are uncovered can create reactions of guilt and self-reproach which in and of themselves may impede the grief process. Planning for the death or for after the death involves active acknowledgement of the fact that death will occur. Around such an act, many of these problematic feelings can arise.

This discussion requires two important qualifications. First, if illness results in unresponsiveness, incommunicativeness, or social withdrawal, it is probable that change of the first subset will also commence prior to death. This may be unaccompanied by the strong guilt feelings one would otherwise expect. Second, if from utter hatred the

family member truly wishes the dying patient to be dead, and has no mechanism of conscience to modulate, the same may hold true.

Encapsulation, including both aspects of the world view, may take place. Factors that would favor this outcome are the reverse of those favoring abandonment. If the fact "the person will be alive" is extremely important to the family member, if there is little preparation, if the change is unwanted, or if there is lack of any view of the world as provisional, the transition to "the person will not be alive" may be very difficult and not started at all. Persons with certain personality characteristics--overcontrolled neurotics (Janis, 1958)--who are less able to tolerate change, might tend to react to threatened loss with encapsulation, at least temporarily. However, progressive deterioration of health and social interaction that accompany the terminal illness would make this subset more and more difficult to hold onto. If such encapsulation does persist, then one would expect to see little or no grief reaction prior to death.

In summary of this section, prior to death of the patient, the family members will generally begin to face the fact that their loved one will not be alive. This involves a major change in the assumptive world model that encompasses the sick person. Some form of grief reaction is likely to accompany this. Under most circumstances, the family will not abandon or otherwise change the subset of the world model that includes "the person is alive." If the family member begins neither transition, problems may arise as the illness worsens. If both transitions are worked through, socially pathological sequelae with accompanying guilt and ambivalence are likely to occur. Planning for the death or after the death may evoke many of the same problematic feelings. It is not surprising, then, that many persons make few preparations during



the terminal illness of a loved one, even though they may have been informed of impending death.

## I.C. Effects of Bereavement on Health and Well-Being

### I.C. 1. Mortality of Bereavement

The most striking evidence of the morbid sequelae of grief and bereavement comes from studies of mortality. These have taken several forms. Some authors have looked at vital statistics, some at death certificates, and some at cohorts of subjects followed retrospectively or prospectively. These studies have been rigorously reviewed epidemiologically by Jacobs and Ostfeld (1977).

Kraus and Lilienfeld (1959) studied the relationship between marital status and mortality from National Office of Vital Statistics data for the years 1949-1951. For every age group, lower death rates were noted for the married than for either the single, widowed or divorced. Ratios of widowed to married rates varied from 1.8 to 3.7 for women under 45 and from 2.9 to 4.3 for men under 45. For specific diseases, namely heart disease, arteriosclerosis, stroke, tuberculosis, and pneumonia, the risk was more than five times that for the married; for some diseases and age groups the rates reached ten times or more the married rate. Race was related to mortality; whites under age 35 had higher mortality ratios than nonwhites, but above that age the relative risk for nonwhites was higher.

In one of the first systematic studies of mortality using death certificates, Ciocco (1940) analyzed cause of death in white widowed and married persons in Washington County, Maryland for the years 1898-1938. In total, 2578 couples were examined. The mean ages were 68.8 years old for husbands and 68.1 years for wives. A high correlation was found between the length of life for husbands and wives, whether or

not they died from the same causes. Higher than expected incidences of death from the same cause between spouses were found to involve tuberculosis, influenza and pneumonia, cancer, and heart disease. Heart disease was the most common cause of death overall, and 25-30% of the spouses of heart disease victims also succumbed to it. Ciocco proposes various reasons why both spouses might be more likely than expected to die from the same cause. A problem with the study is that the time interval between deaths was not controlled and averaged in excess of nine years.

MacMahon and Pugh (1965) looked at the death certificates of widowed Massachusetts residents who committed suicide and analyzed length of widowhood. Using the incidence of suicides in later years as a basis for comparison, suicides tended to cluster in the first four years of widowhood, particularly the first year. Relative risk of suicide was higher in men than women. It was thought that remarriage among those not committing suicide might account for this clustering pattern, but there was little difference in frequency of remarriage following widowhood between a group of married persons committing suicide and a matched group dying from other causes. MacMahon and Pugh concluded that there is a significant unexplained increased risk of suicide in the first four years of widowhood.

Cox and Ford (1964) looked at the death certificates of 60,000 women awarded widows pensions in England in 1927, all under 70 years old. There was a significant increased relative risk of mortality in the second year of bereavement, when compared with the risk over five years for widows as a whole. The data may have been biased, however, by widows who died or were too sick to apply for the pensions, particularly during the first year.

Young, Benjamin, and Wallis (1963), and later Parkes, Benjamin, and

Fitzgerald (1969) examined death and cause of death in 4486 English widowers, aged 55 years and older at the time of their wives' deaths in 1957. The group was followed for a total of nine years. Of the group 213 (4.7%) died within the first six months. There was a 40% increased risk of death above married men of the same age during that time. Thereafter, the death rate fell rapidly towards the level for married men, and after the fourth year, dipped slightly below the married rate. The dip in mortality in later years was thought to be compensatory for the marked increase in the first year. The greatest increases during the first six months were found in widowers dying of myocardial infarction or atherosclerotic heart disease; for these the increased risk was 67% above the expected rate for married men. 22.5% of deaths were from the same diagnostic grouping as the wife's death, but this was not significantly different from expected. No significant relationship was found between mortality and social class.

The studies by Cox and Ford (1964) and Parkes and Associates (1969) suggest different patterns of mortality for widows and widowers. This was supported by McNeill (1973), who studied death certificates of 9247 men and women aged 20-74, widowed in Connecticut in 1965. Though retrospective in data collection, by analysis of death certificates for each subsequent year, this group was followed "prospectively." Significant patterns of mortality rates adjusted for both sex and age were noted for both men and women. Specifically, men under 60 years old were at highest risk of death in the first six months after bereavement, while women under 60 years old were at highest risk in the second year following bereavement. In the first six months, widowers were at significant excess risk of death from heart disease and suicides and accidents, while

widows had excess mortality from heart diseases. In the second six months, widows were at excess mortality from malignant neoplasms. Both sexes were at higher risk of mortality from cirrhosis and alcoholism during the second and third years following bereavement.

In the largest cohort study, Rees and Lutkins (1967) followed 903 survivors of 371 deceased persons living in Wales and compared their mortality with 878 close relatives of 371 married persons matched by age, sex, and residence location with the deceased. In the first year following bereavement, there was a seven-fold risk of mortality in bereaved relatives above that of the control group. Mortality was significantly greater in males than females. The relative risk was highest for widows and widowers--the risk was ten times the risk for married persons in the first year. The risk of death in the survivors was doubled if the deceased died in the hospital versus home, and increased higher if the death occurred elsewhere. There was a tendency noted for the bereaved who died to be slightly younger than the deceased, suggesting that younger than expected subjects may have contributed more to the high relative risk. A possible bias to the study that is unexplained is the relatively low mortality (0.68%) in the 878 controls during the first year of the study.

Of the other cohort studies, some of which will be discussed in the section on morbidity, only one shows evidence of increased risk of mortality. Shepherd and Barraclough (1974) studied a small group of 44 persons whose spouses had committed suicide four to seven years previously. 10 (23%) of this group had died during that time, double the expected age- and sex-adjusted rates. Of note is that half of these were "mortally ill" at the time of the suicide. In other studies (Clatyon, 1974;

Ward, 1976) there is no evidence for increased risk of mortality in the bereaved.

### Summary of Findings and Interpretation

Jacobs and Ostfeld (1977) summarize the findings of these studies. For both men and women, there is an excess risk during the first two years. For men, this risk is highest in the six months following the loss. From retrospective studies, the excess risk is highest in the young. In men and women, there is evidence of excess mortality from tuberculosis, cirrhosis, alcoholism, accidents, and heart disease. In women of all ages there is also excess mortality from cancer. Men have excess mortality from pneumonia, influenza, and suicides. Other disease processes may also be important. Risk of suicide is elevated for several years following bereavement. Most other illnesses show a dip in mortality rates below expected values in the fourth or fifth years following bereavement, possibly as compensation for the excess mortality from such diseases in the first two years.

Risk of mortality is influenced by several factors. Men are at consistently greater risk than women. By retrospective studies, younger bereaved appear to be at greater risk than older. Relationships to the deceased may be important; from one study (Rees and Lutkins, 1967) the effect of loss of parent or spouse was more severe than those of loss of siblings or children. Preexisting illness in the bereaved may be associated with excess mortality. Kraus and Lilienfeld (1959) found an association between race and outcome; whites under 35 had greater excess risks than nonwhites; over age 35 that reversed. There is no evidence that increased risk of mortality is related to the length of the spouse's

terminal illness. Rees and Lutkins (1967) noted site of death as a determinant of mortality for survivors, but as Jacobs and Ostfeld point out, this is probably dependent upon other contributing variables, including socioeconomic status and preexisting illness. Jacobs and Ostfeld note that the effect of the socioeconomic status has not been well investigated. In prospective studies, age and race have also not been adequately considered, so that controlled data to support retrospective analyses does not exist.

Jacobs and Ostfeld summarize and discuss other interpretations for the increased mortality; some of these could also affect morbidity in spouses and other family members of the terminally ill. Homogamy, or marital selection of ill or potentially ill spouses by each other (Ciocco, 1940) does not seem to affect mortality. Most of the illnesses causing excess mortality in the bereaved start long after marriage. Mutual selection based on personality factors, nervous habits, or relationship with parents could play a part in mutual disease susceptibility. These have been implicated in a large prospective study of susceptibility to serious illness in a mostly young male group of medical students (Thomas, 1976). Marital selection might have also been based on shared preferences for diet and stressful, or toxic stimuli.

Similarly, joint unfavorable environment (Kraus and Lilienfeld, 1959) may contribute to the development of disease in the surviving family. This could include exposure to the same environmental toxins (cigarettes, pollutants), shared general family stress, shared life events, shared accessibility to preventive or informative health care, shared attitudes towards health care, and socioeconomic status. All of these could also contribute to morbidity before or after bereavement. In Ciocco's 1940

study, infectious diseases were an important cause of mortality. From more current data, however, this probably contributes little to morbidity.

Jacobs and Ostfeld point out that social isolation and retirement may contribute to social stress after bereavement; both may be important sources of social stress prior to bereavement. Social isolation could exist during prolonged hospitalization, periods of withdrawal, or incommunicativeness of the sick person, particularly when other social or family support is lacking. A large proportion of spouses of the chronically ill who take major home care responsibilities are forced to leave employment (Cartwright and Associates, 1973, pp. 155-157), which would tend to add to the isolation.

Loss of care provided by the deceased could certainly affect the health of the spouse prior to bereavement. This would occur when illness or disability interferes with the terminally ill person's care-giving role towards the spouse. If nobody else is available to take that responsibility, and the spouse has had difficulties assuming such responsibility for his/her own care, then his/her health care would be likely to suffer. This also applies to the control of destructive habits or acting-out behavior in the spouse. If the spouse cannot develop self-control and nobody else is available who can control such behavior, he/she is liable to get into trouble.



## I.C.2 Atypical Grief Reactions: Psychiatric and Psychosomatic Illness

The first systematic study of morbidity and symptomatology associated with grief was Lindemann (1944). He studied 101 subjects: psychoneurotic patients bereft of relatives while in psychotherapy, relatives of patients dying in the hospital, bereaved disaster victims, and relatives of persons who died in the armed forces. Somatic and psychological distress in this sample was then characterized. His observations of the symptomatology of typical or normal grief have been reviewed by Engel (1961) and have already been presented here. Of interest in this section are his observations of "morbid" or atypical grief responses.

Lindemann noted three basic atypical responses: absent, delayed, and distorted reactions. The latter two are described as morbid. Delayed reactions appeared to be most common when the subject was confronted with important tasks in the post-bereavement period. Distorted grief reactions included a wide variety of symptoms comprising social, somatic, and psychological problems. Social problems included:

- (1) alterations in relationships with friends and relatives,
- (2) lasting loss of social interaction, and
- (3) activities detrimental to social and economic existence.

Somatic problems included:

- (4) the development of psychosomatic diseases.

Psychologic problems included:

- (5) overactivity without a sense of loss,
- (6) acquisition of the last symptoms belonging to the deceased,
- (7) furious hostility,
- (8) rigidity of personality--usually to compensate for the hostility,

and

9. agitated depression.

The latter reaction occurred in only a small percentage of subjects. Prior history of depression combined with obsessive personality traits was associated with its development. Both the intensity of interaction with the deceased and the significance of the dead person in the social system contributed to the severity of the grief response. Lindemann noted that morbid reaction usually took place in individuals without prior history of psychoneurotic disease.

In a retrospective study, Marris (1958) examined the effects of bereavement and mourning in 72 London widows of an average of 42 years. The primary focus of his study was the social milieu of the mourning process, and he demonstrated the social and financial desolation that was the lot of many of these widows of working class husbands. His characterization of grief symptomatology differs little from that described by Engel. His subjects mentioned a variety of somatic symptoms which they claimed had started or worsened as a result of their grief. These included weight loss, rheumatism, fibrositis, asthma, bronchitis and chest pain, peptic ulcer, indigestion, swollen feet and leg ulcers, falling hair, skin irritation and rashes, gum abscesses, headaches, dizziness, and nervousness. 31 (43%) considered that they had sustained lasting deterioration in their health.

In a more recent study of the processes of grief and mourning, Gorer (1965, pp. 63-91) interviewed 80 British men and women bereaved within five years of close relatives. He characterized seven "styles" of mourning after death. These were:

- (1) Denial of mourning, which was associated with strong

religious belief in continued life after death.

- (2) Absence of mourning, where the person felt no need to grieve at the time of death or thereafter. All cases were related to the deceased as sibling or child, and never spouse. The reasons underlying absence of grief usually involved distant or negative feelings towards the deceased.
- (3) Time-limited mourning, which is equivalent to normal grief. and almost always involved a definite period of intense active grieving.
- (4) Hidden mourning, which is comparable to Lindemann's over-activity without a sense of loss. Actually, the loss was felt, but the increased business served to focus attention away from painful feelings of grief. The result was marked prolongation of the overall process.
- (5) Unlimited mourning without despair, which was basically a prolonged reaction without severe accompanying psychological disturbance.
- (6) Unlimited mourning with "Mummification," where the possessions of the deceased and layout of the house were preserved exactly as they existed before death. This is the outward expression of Parkes' (1975a) third type of psychosocial transition, encapsulation.
- (7) Unlimited mourning with despair, in which prolonged psychological disturbance with depression and hopelessness was manifest.

Of the 9 (12%) subjects characterized by Gorer as having unlimited mourning with despair, 7 had not engaged in any formal ritualistic

mourning for the deceased. Gorer doesn't give any percentages for the remainder of those he interviewed regarding this variable, but he does conclude that there is likely an association between the presence of funeral, burial, and mourning rituals and more favorable outcome.

Looking at a different aspect of morbidity, Parkes (1964a) analyzed the medical records of 44 unselected widows of mean age 60 years, followed by London general practitioners. The eighteen months following bereavement was broken down into three six-month time periods, and the period twenty-four months to six months prior to bereavement was taken as a control period. During the control period, the average number of consultations per widow per six month period was 2.2; this increased with age. Only one subject did not consult the physician during the period of the study.

The results demonstrate increased physician consultation rates following bereavement. In the first six months after bereavement, widows less than 65 years old had more than three times the consultation rate of the control period for psychiatric symptoms. Also for these younger widows, the rate of prescription of sedatives was seven times that of the control period. Both of these were highly significant. Widows aged 65 years or older did not show this, but did show a significant increase in consultation rates for non-psychiatric symptoms. In addition, physicians' records showed that these older widows tended to show less social withdrawal and overt grief symptoms than the younger widows. There was significant increase in consultation rates for muscular and articular problems for women under 65 years old. There are no significant differences noted between subjects whose husbands' deaths were expected or unexpected. Only three of the subjects required hospitalization for

Cartwright, Hockey, and Anderson (1973) interviewed 785 men and women who were relatives of people who had died three months or nine months before. The study focussed on characteristics of the sociologic and economic context of the terminal illness. Of interest in this section are statements about help seeking in the bereaved (pp. 195-197). The overall proportion of subjects consulting physicians after bereavement was 51%. This proportion decreased from 59% for subjects under age 65 to 45% for those over age 75. The proportion prescribed medication for shock, anxiety, or nerves also decreased slightly with age. Husbands and wives differed in contact with medical practitioners. While roughly equal proportions of the 94 widowers and 204 widows consulted general practitioners or other professionals in the time since bereavement (67% vs. 59%), a smaller percentage of husbands than wives felt that such consultations were connected with the bereavement (32% vs. 52%), fewer were visited by their doctor (16% vs. 37%), and fewer were prescribed medication for shock, nerves, or sleeplessness (23% vs. 36%).

The severity of the terminal illness had little effect on physicians' consultations connected with the bereavement. On the other hand, 60% of relatives of patients not restricted during the illness were prescribed medicine, while only 35% of relatives of patients who had been severely restricted three months or longer before death were prescribed it. This suggests that the impact of bereavement or the subsequent grief reaction was more severe for relatives of patients who were not restricted before death.

The elderly are poorly represented by many studies that report symptomatology. There is some question of whether grief takes on a different reaction pattern in the elderly.

Stern and Williams (1951) interviewed 25 subjects, 24 of them women, aged 53-70 years old. Few of the manifestations of grief described by Lindemann (1944) and others were noted. Few expressed conscious guilt feelings. Somatic illness was common. Potential psychological disturbances included bizarre idealization of the image of the deceased, irrational hostility towards living persons nearby, and tendencies toward self-isolation.

In another study of reaction to bereavement in the elderly, Heyman and Gianturco (1973) followed 256 men and women over 60 years old (mean age 74 years) in a longitudinal study of aging. Of these, 27 women and 14 men became widowed. Social adjustment, attitudes, psychological assessment, and physical functioning, before and after bereavement, were analyzed, but no significant differences were found. There were no significant differences between men and women. A possible finding relates to depression. Of 20 women evaluated as not depressed before bereavement, 4 became depressed after bereavement, while no nondepressed men became depressed. Women may be more affected than men, but the numbers here are too small to draw any definitive conclusions. In general, the widowed group was characterized as having emotional stability, stable social networks, relatively few life changes, and only time-related health deterioration. Ongoing involvement in religious groups seemed to be important in helping individuals maintain activity and social functioning after bereavement.

Several studies explore the association between bereavement and mental illness. Stern and LaRivière (1957) studied 38 young and middle-aged patients admitted after bereavement to a Montreal psychiatric hospital. They noted a high prevalence of grief-related symptomatology:

fatigue, anorexia, weight loss, and insomnia. Parkes (1972, p. 210) interviewed 18 inpatients and 3 outpatients at two British psychiatric hospitals. All had been recently bereaved. Comparing 14 of the patients who were less than 60 years to data from several other studies of non-psychiatric bereaved subjects, including Marris (1958), there was considerable similarity in the incidence of the major grief symptoms. A significant difference, though, was a markedly greater incidence of ideas of guilt and self-reproach in the psychiatric than nonpsychiatric subjects (79% vs. 11% of Marris's 72 widows). There was also a higher incidence of social withdrawal in the psychiatric patients (64% vs. 38%).

Looking at the problem on a much larger scale, Parkes (1964b) reviewed case notes on 3245 patients admitted to the two psychiatric hospitals from 1949 to 1951. 94 patients (2.9%) had had onset of their illnesses within six months of the loss of parent, child, spouse, or sibling. Based on age-specific attack rates from vital statistics, Parkes estimated the expected rates in this population of bereavement from different relatives. It was found that the number bereft of a spouse was six times the expected rate. Among the bereaved, there was also a preponderance of women over 40. The sex difference was unexplained by sample bias, implying that older women fare more poorly and require hospitalization significantly more frequently after bereavement than men.

The incidence of all affective disorders was significantly higher for the bereaved than nonbereaved controls. Within this category, a significantly higher proportion of the bereaved than nonbereaved suffered from reactive depression (28% vs. 15%). Other, more serious psychiatric conditions also occurred: 8% were diagnosed as having

schizophrenia and 20% as having manic-depressive psychoses. These were not significantly different from controls.

Stein and Susser (1969) examined psychiatric illness attack rates in the married and widowed among 1945 persons seeking psychiatric treatment at a clinic in Salford, England. They found that the incidence of widowed men was 2.7 times the incidence of married men. For women, the ratio was 1.7. Those patients requiring psychotherapy were significantly more likely than expected to have been bereaved within five years. Widows seeking care for depressive illnesses had 1.8 times the rate for married women. Widowers seeking treatment for problems of addiction, largely alcoholism, had 7 times the rate for married men.

Any overall causal relationship between bereavement and mental illness implied from these two studies, however, may be misleading. Crisp and Priest (1972) administered the Middlesex Hospital Questionnaire, a measure of neurotic illness, to 777 subjects in a general practice population, aged 40-65. He compared responses of 65 women and 64 men who were bereaved of close relatives for less than one year with responses of the remaining non-bereaved population. Looking at scores by sex and relation to the deceased, the only significant differences noted were in 31 males and females who had lost relatives outside of the immediate family; males had higher scores on the Somatic scale while females had higher scores on the Hysteria scale. There were no differences noted for the conjugally bereaved. For the subgroup of bereaved aged 50 years or less, though, those who had lost a parent of the opposite sex during the prior year had significantly higher scores on the Anxiety scale than did those who had lost a parent of the same sex.

The authors were surprised at the results of the study. They had



expected significantly higher scores among the bereaved, indicative of those seen in psychiatric populations, but these did not occur. This implies that bereaved subjects needing psychiatric care are probably not representative of bereaved subjects overall. As shall be seen, it also supports evidence from prospective studies that such needs are uncommon in the bereaved.

The last study in this section examined the long-term effects of suicide on survivors. Shepherd and Barraclough (1974) studied 34 spouses of people who had committed suicide four to seven years before. 14 subjects with better psychosocial outcome were compared with 14 with poorer outcome. In this study, the poorer outcome group was significantly older than the better outcome group (mean age of 52 vs. 40 years). Subjects also tended to have better outcome when the spouse had suffered from alcoholism, abnormal personality, hypochondriasis, or prolonged illness. Five spouses had been terminally ill prior to the suicide. A history of prior suicide attempts or threats was associated with better outcome. Subjects who had been separated from their spouses for a long time prior to the suicide also fared better. The actual level of involvement between spouses around the time of the suicide is unknown. Only one subject required psychiatric treatment for reasons commencing after bereavement. From the data, it would seem that illness in the deceased spouse and open conflict in the marriage are associated with better long-term outcome following bereavement from suicide. Shepherd and Barraclough concluded that their cohort suffered no more morbidity than would be expected for a comparable unselected widowed group.

### I.C. 3 Controlled and Prospective Studies

Over the past 15 years, three groups of investigators have performed controlled, prospective cohort studies to elucidate somatic and psychological morbidity following bereavement and the factors that contribute to it. These studies will now be reviewed. Also included will be descriptions of several related uncontrolled studies and several intervention studies which test out hypotheses based on the prospective studies. All of these provide information that is applicable to the circumstances of the family members of the terminally ill.

#### Studies of Maddison and Associates

Maddison and Viola (1968) analyzed self-report postal health and social questionnaires from 375 Boston and Sidney widows of average age 49, thirteen months following bereavement. The results were compared with those from 199 age- and socioeconomic-status-matched married controls. Health deterioration was measured by the sum score of 57 possible symptoms experienced by each subject. Each symptom was weighted by its innate seriousness and assigned an initial value of 1-4 units. If the subject had sought medical attention for it, 2 units were added, and if the subject had been hospitalized for it, 2 more units were added. Marked health deterioration was defined as having a score of 16 units or more. 21.2% of Boston widows and 32.1% of Sidney widows were found to have marked health deterioration, and both were significantly higher than controls. The significance persisted, even when the weighting for medical consultation and hospitalization was eliminated.

In the thirteen months following bereavement, a multitude of

general and specific symptoms had occurred in a significantly higher percentage of the widowed than control groups. Psychological, neurological, and gastrointestinal symptoms were most frequently represented. Those present in 20% or more of the widowed group were relatively few: general nervousness (41%), depression (22.7%), insomnia (40.8%), reduced work capacity (46.7%), and gross fatigue (29.6%). Other symptoms are listed in Table III, below. (Section I.C.4). Conditions suggesting organic disease were present infrequently (less than 5% of subjects). These included peptic ulceration, colitis, asthma, frequent infections, neoplasm, and diabetes. Only 12.7% of subjects had depression requiring medical treatment, and only 1.3% required hospitalization for it.

There were significant differences in drug intake and habits between bereaved and control groups. 37.3% had increased their use of medications while 5.9% had increased it markedly. Sidney widows tended to respond in this way significantly more frequently than did Boston widows. Alcoholic intake increased in 6.7% of widows. 11.7% markedly increased their use of tobacco. The incidence of increased alcoholic intake was significantly greater in Boston widows than Sidney widows.

Health deterioration was significantly related to the ages of the widow and her husband. Younger age was associated with greater deterioration. There were no significant associations involving socioeconomic status, warning of death, number of children, number of young children, or religion.

From the 132 Boston widows, Maddison and Walker (1967) interviewed 20 good- and 20 poor-outcome subjects thirteen months after bereavement and compared responses. Of particular interest was information about the subjects' perceptions of their interaction with the environment.

The poor-outcome subjects tended to perceive the environment as failing to meet their needs during the crisis, while the good outcome group perceived their social support as helpful. The poor-outcome group tended to appreciate active encouragement from the environment, but also tended to perceive those around them as being actively unhelpful. Of particular concern to them were situations in which others seemed to block affective expression of grief, acted overtly hostile towards the widow, or attempted to focus the widow's attention away from the past.

Maddison (1968) notes other characteristics associated with poor outcome in these subjects. The presence of dependent children was associated with poor outcome, but not significantly so. There was no overall association between the quality or pathology of the marriage and outcome, but one subgroup with definite sadomasochistic aspects and considerable ambivalence did fare more poorly; overt neurosis predating the husband's death was associated with poorer outcome. Though rare in Maddison's subjects, the presence of multiple life crises in the year following treatment was associated with poor outcome. Subjects having disturbed relationships with their mothers, if alive, tended to do poorly. Deliberate suppression of affective grief response by a subject, present in a few women, was always associated with poorer outcome. On the other hand, denial of dependency needs, present in about 40% of those interviewed, was not associated with poorer outcome.

Out of this work has developed several programs aimed at active intervention in the bereaved. The Widow-to-Widow program (Silverman, 1969) has been functioning for several years, offering peer support from other widowed to the recently bereaved in the Boston area. Such support seems to be effective at preventing poor outcome in widows who

might be expected to have trouble. Walker, MacBride, and Vachon (1977) have described effectiveness with a similar widow peer-support organization in Ontario. Applying social network theory to the crisis following bereavement, they suggest that such peer support strengthens important weaknesses in the social support system. In particular, widows can offer each other strong emotionally supportive ties early after bereavement and bridging ties to new social contacts later, that might not otherwise exist. In a controlled study of intervention, Raphael (1977) identified four indices, based on Maddison and Walker's 1967 study, that characterize widows at high risk for poor outcome. They are:

(1) A high level of nonsupportiveness in social network response during crisis.

(2) A moderate level of nonsupportiveness, combined with traumatic circumstances of death, including untimely, unexpected, anger-provoking or guilt-provoking death.

(3) Previously highly ambivalent marital relationship with the deceased, combined with tragic circumstances of death, and any unmet needs.

(4) Presence of any concurrent life crises.

200 self-selected Australian widows applying for social security benefits were screened. Using the above criteria, Raphael assessed 64 of these to be at high risk and assigned them randomly into two groups: 31 experimental subjects to receive intervention and 33 controls not offered any. Intervention consisted of support for expression of grieving affects, facilitation of the mourning process, review of positive and negative aspects of the relationship, and discussion of the needs of dependents. The questionnaire of Maddison and Viola (1968) was administered

to both groups at thirteen months. The same weighting system described above was used in scoring. Of the 27 experimental subjects followed up, 21 (78%) had good outcome, as compared with 12 (41%) of the 29 controls followed up. 98 (80%) of the 122 residual non-high-risk, non-intervention subjects followed up had good outcome. The difference was significant between the experimental and control groups and highly significant between the control group and the residual group. Thus, on the basis of Maddison and Walker's criteria, preventive intervention can indeed positively affect outcome.

#### Studies of Clayton and Associates

In an uncontrolled study, Clayton, Desmarais, and Winokur (1968) investigated the somatic and psychological symptomatology of grief in 40 adult men and women whose close relatives had died at St. Louis hospitals. Most of the interviews were completed within ten days of bereavement. Depressed mood, crying, and sleep disturbances were present in more than half the subjects. Difficulty concentrating, loss of interest in TV or news, and anorexia/weight loss were also frequently present. About one third of subjects started taking drugs for nerves or sleep and 55% started drinking, but nearly all had done so before. Symptoms varied little with differences in subject characteristics, but there were several that reached statistical significance. A significantly higher proportion of women than men cried and used sleep or nerve medicines. A higher proportion of older subjects (over 60 years old) than younger admitted to difficulty concentrating. Comparing length of illness of the deceased (shorter or longer than six months), anorexia/weight loss was present in a higher proportion of subjects where the deceased's

illness was shorter. At followup one to four months later, 81% had improved. Only one subject was worse and only one subject had sought psychiatric help.

Clayton, Halikas, and Maurice (1971) examined symptomatology and health-seeking behavior by interviewing 109 St. Louis widows and widowers one month after bereavement. The subjects ranged in age from 20 to 89 years, and the mean was 61 years. As in their 1968 study, crying, depressed mood, and sleep disturbances were found to be the cardinal symptoms of bereavement, each occurring in over 80% of subjects. Sleep disturbance was most common in women. Guilt feelings were present in 34% of subjects less than 60 years old, but in only 12% of older subjects. Anxiety attacks, suicidal thoughts, fear of losing one's mind, and hostility were uncommon symptoms. 52% were found to take medicine for nerves or sleep. Only 15% had sought medical attention from a physician.

In a study of the same group, Clayton, et.al. (1972) matched the symptoms of the bereaved to diagnostic criteria of depression as specified by Feighner and Associates (1972). 35% of the subjects were found to have a symptom complex diagnostic of clinical depression. Comparing this group with 53 nondepressed bereaved subjects, the authors only found one important differentiating characteristic: fewer of the depressed group had close adult children living in the area. Age, sex, previous treatment for depression, family history of psychiatric illness, or presence of alcoholism did not differentiate the groups significantly.

90 of the subjects were reinterviewed thirteen months following bereavement and compared with married age- and sex-matched controls (Clayton, 1974). Subjects and controls were questioned about physical and

mental symptomatology during the prior year. 83% of the widowed had seen a physician, 61% more than three times, and 23% had been hospitalized. 51% had taken medicine for their general health, 30% had taken pills for sleep, and 32% had taken tranquilizers. Despite these large percentages, only the percentage of subjects who had taken pills for sleep was significantly greater than that for the control group. Only 10% of the bereaved admitted to general poor health over the prior year.

Symptoms elicited from this study are listed in Table III below (Section I.C.4). Of the symptoms present significantly more frequently in the bereaved than control group, most are characteristic symptoms of grief or depression. Over 90% of subjects had experienced one or more of these. Two symptoms possibly connected with the grief reaction were feelings of guilt (27%) and auditory or visual hallucinations (12%). The only physical symptoms which occurred significantly more frequently in the widowed were blurred vision (25%), shortness of breath (28%), and palpitations (17%).

Using the diagnostic criteria of Feighner and associates (1972) again, Bornstein and associates (1973) compared depressed and non-depressed subjects and found several important differences. A significantly greater percentage of those depressed reported general poor health, dizziness, blurred vision, and chest pain. Fewer of them lived with their families, fewer were religiously observant, more had low income, and fewer had experienced prior death among relatives in their lifetime. A greater proportion of those depressed at thirteen months had been depressed by the same criteria at one month as well.



Clayton and associates (1973) examined the same group of 109 widows and widowers to determine if outcome was affected by length of the terminal illness or by the presence of an "anticipatory grief" reaction. The latter was defined by the presence of a depressive symptom complex prior to the death. This was elicited by questioning the subject one month after bereavement. If the symptom complex was present after bereavement, it was considered as a "normal depressive reaction." Sudden deaths (less than five days of terminal illness) were excluded. Subjects whose spouses' illnesses lasted more than six months were compared with those whose spouses' illnesses were shorter. Symptomatology one month after bereavement differed little between the two groups.

Eliminating subjects with sudden death left 81 subjects. 19 (23%) of these were found to have had the depressive symptom complex during the spouse's illness. Of these, 13 (68%) were depressed at one month. Of the 68 who had not been depressed prior to bereavement, only 15 (24%) were depressed at one month. This is statistically highly significant and implies a significant association between depression prior to and at one month after bereavement. At thirteen months, though, neither anticipatory depressive symptom complex nor length of illness made much difference in outcome. This implies that, whatever the process is that causes depression at one month, it tends not to have long-lasting effects.

From this one might surmise that anticipatory grieving would predispose an individual to a more intensely depressive grief experience shortly after bereavement. As discussed in Section I.A., a problem with this study is the retrospective nature of collection of data from the period prior to bereavement. Since the data was collected at one month, it is possible that depressed and still grieving subjects would distort

their memories of feelings experienced during the terminal illness. Thus these results must be interpreted cautiously.

A second problem with Clayton and her associates' analysis is their breakdown of illness length. For some subjects, several months or even several weeks could be more than enough time to develop an anticipatory reaction which alter subsequent post-bereavement grieving. As will be demonstrated by other studies, the exclusion of extremely short illness lengths probably limited the short- and long-term morbidity observed in the short illness group.

#### Studies of Parkes and Brown

In a comprehensive prospective controlled study, Parkes and Brown (1972) interviewed 68 Boston widows and widowers and carefully matched controls, under the age of 45. The average age was 36 years old. Subjects and controls were interviewed a total of five times: at approximately three weeks, six weeks, thirteen months, fourteen months, and two to four years after bereavement. Interview questions came from a variety of sources, including the Midtown Manhattan Study (Srole and associates, 1962), and covered social, psychological, and physical adjustment. Responses were grouped into different scales by factor analysis and common sense methods. Psychological and physical health data from the third, fourth, and fifth interviews was analyzed.

Disturbances of sleep, appetite, and weight were significantly more common among the bereaved during the year. Both widows and widowers were significantly more depressed than non-bereaved men and women by depression scores as well as by individual questions. Over 50% of subjects had one or more symptoms of depression. Widowers admitted significantly more somatic symptoms than did controls, but this was not true

for women, Looking at autonomic nervous system symptoms, the bereaved admitted to an average of twice the number of symptoms as controls. Women from both bereaved and control groups had higher numbers of such symptoms than men. There were no significant differences noted for other symptom groupings or for general health.

28% of the bereaved admitted to smoking more over the prior year, and 28% admitted to increasing alcoholic consumption. 26% had started taking tranquilizers. All of these are significantly increased above controls. 22% of the bereaved started taking drugs for sleep, but this was not significantly different from controls.

Utilization of health and supportive services was examined. 18% of the bereaved had been admitted for various reasons to hospitals, while 22% of widows had spent more days sick in bed. Both were significantly increased above controls. There was, however, no increase above controls in the number who consulted physicians. About 40% of both groups had consulted physicians three or more times during the preceding year. A significantly higher percentage of bereaved women (39%) than controls admitted to seeking help for emotional problems from physicians or other professionals (minister, social worker, psychologist). The same was not true for men. About half of those seeking professional help for emotional problems had not done so before.

Besides depression, psychological and personality scales did not differentiate significantly between bereaved and nonbereaved. The investigators did, however, analyze eleven individual items that differentiated the two groups. In general, the bereaved group seemed to be more under strain and had more restlessness, indecisiveness, and trouble with memory. They also saw themselves as being more distant or remote

from others around them, Possibly contributing to the strain were loss of income and family ill health. The bereaved had suffered significantly more frequent loss of income than controls during the prior year. 55% of widows, versus 24% of nonbereaved women had members of their families hospitalized during the year; this was significant.

By long-term followup at the fifth interview, autonomic and depressive symptoms in widows had declined steadily until there was little difference between bereaved and controls. Widowers, on the other hand, were still significantly more depressed than married men. There were eight individual items that differentiated the bereaved from nonbereaved at this time. They characterize the bereaved as being more independent, self-reliant, and detached, distant, or remote from friends, world affairs, and new relationships. Parkes suggests that this process is comparable to Cumming and Henry's (1961) "disengagement," observed as part of the normal aging process.

In response to Clayton and associates' study of anticipatory grief (1973), Parkes (1973) applied the depressive symptom complex to this data. He refuted the notion that length of terminal illness has no effect on outcome. Comparing the thirteen month outcome of 24 subjects with preparation of less than two weeks with that of 46 with longer preparation, Parkes found that significantly more of the short preparation group (74%) than the long preparation group (42%) were still depressed. The short preparation group fared generally more poorly, with significantly more anxiety and self-reproach than the long preparation group.

At long term outcome, two to four years after bereavement, the short preparation group had significantly poorer outcome by several in-

dices (Parkes, 1975d). Significantly fewer were psychosocially well adjusted, as judged by remarriage, role functioning, financial affairs, evidence of acceptance of the death, and attitude towards the future. This is evidence of the long term ill effects of little or no preparation for the death of a spouse.

It should be noted that Parkes included subjects whose spouses' illnesses were extremely short, whereas Clayton did not. It is probable that many of these may account for the increased morbidity Parkes observed. In addition, Parkes suggests that a primary difference between the two samples is one of age. He suggests that in his younger group, longer preparations may have been of considerable importance for mitigating the long-term effects of bereavement. In Clayton's older group it may have made less difference in final outcome.

This hypothesis is supported by a study by Ball (1977) of the impacts of age and suddenness of death on grief reactions and symptomatology. She studied 81 Sacramento, California widows who returned a postal questionnaire sent six to nine months after bereavement. Of the 200 widows sent the questionnaire, this represents a 41% return rate. Widows were divided into young (18-46), middle (47-59), and old age groups, and short (five days or less) and prolonged (more than five days) illness groups. Overall, more than half of the subjects reported loss of appetite, sleeping problems, tiredness, and restlessness. 48% admitted to medication use, 27% moderately or frequently.

Young age and suddenness of death were both significantly associated with high overall severity of the grief reaction. Younger, but not middle-aged or older widows, also had significantly greater severity of symptoms, particularly restlessness. Younger widows bereaved after short illnesses had

significantly higher irritability than other groups. The author concludes that in the young aged group (18-46 years) a period of preparation prior to death appears to mitigate the intensity of the grief response. This does not seem to be true for older widows.

In the preliminary results from an intervention study, Polak and associates (1975) demonstrated indirectly the magnitude of the problem facing survivors of sudden death victims. Preventive crisis intervention, similar to that already described in other studies, was offered to 39 families of persons dying suddenly in the Denver, Colorado area. Control groups consisted of 66 similarly bereaved and 56 nonbereaved families, none of whom were offered intervention. Individuals in the intervention group were matched by age, socioeconomic status, education, and residential location with individuals in the control groups. Physical illness, psychiatric illness, family functioning, and personality indices for family members were measured shortly after bereavement and at six and eighteen months after the death. In addition, subjects were interviewed at that time and asked about psychosocial and financial functioning.

The bereaved were found overall to have poorer social and personal adjustment than the nonbereaved. There was little difference in outcome between the experimental and bereaved controls. The authors point out that the experimental group is biased by significantly more suicides and accidents than the control group; however, correcting for this in the data analysis still yielded no significance in the effect of intervention. It was felt that the impact of sudden death was severe, and that crisis intervention made little difference. Though not quantitated, factors observed to be associated with poor outcome in all bereaved included degree of suddenness and violence of death, ineffectiveness and

inflexibility of communication in the family, ineffectiveness or unavailability of social resources, and role playing by the deceased of scapegoat, delinquent, or psychiatric patient. Rigid religious convictions and a healthy level of denial were associated with better outcome. Probably the most important observation offered from the study is that interaction between personal, social system, and environmental factors was crucial in determining outcome. Strengths in one area could counterbalance weaknesses in another. Combined weaknesses in more than one area identified persons at especially high risk for poor outcome.

Parkes (1975c) analyzed the first two interviews of the Boston widows and widowers from the Parkes and Brown 1972 study, to determine other factors that might predict outcome at later interviews. Outcome was measured by combining several indices of social, psychological, and physical adjustment. An important part of this was the subject's scores on ten items from the 1972 study that best differentiated them from nonbereaved controls.

Overall poor outcome at thirteen and fourteen months correlated significantly with low socioeconomic status, lack of preparation for the loss (as described above), and existence of other life crises affecting the respondent. Significant aspects of low socioeconomic status included low weekly income, high number of sisters, and presence of children having problems. The latter was particularly common. 51 (85%) of 60 bereaved individuals with children reported one or more behavior problems. It is unclear whether poor outcome contributed to the behavior problems or vice versa. Life crises affecting the bereaved included pregnancy, divorce, infidelity, and job loss. Some of these might have also been associated with low socioeconomic status.

Severe early psychological reaction to bereavement elicited in the first two interviews correlated with poorer outcome. At the first interview (three weeks), 66% of the bereaved expressed evidence of yearning. Many of these also suffered from fears of breaking down, feelings of unreality, or physical symptoms commonly causing subjects to seek medical care. More in this group were childless and may have tended to experience more loneliness because of it. Though the yearning may have been self-limited in many or most cases, some of this group continued to fare poorly. Even more predictive than yearning were overall negative affect, general psychological disturbance, and overall anxiety as judged by the interviewer. The presence of numbness or tearfulness at this interview did not, however, correlate with outcome.

Reactions at the second interview correlating significantly with poorer outcome included high overall anxiety, overt hostility, persistent nonacceptance of the death, overall negative affect, and feelings by the subject that he would welcome his own death. The relationship of these was not straightforward, though, when ambivalence towards marriage was considered. 45 (66%) of the subjects showed evidence of differences of opinion or repeated problems during marriage. When their responses at the second interview were compared to those of the others, they tended to appear less psychologically disturbed. At thirteen months and at long-term followup, however, they fared significantly more poorly than the group without evidence of ambivalence. The long-term morbidity was most striking in the subgroup of the ambivalent who had long preparation for bereavement. Parkes surmises that marital ambivalence may interfere with normal anticipatory grief processes.

In general, poor outcome at thirteen months consisted of symptoms of chronic or prolonged grief, with persisting anxiety and depression.



Other factors which correlated highly with poor outcome included guilt/anger and feelings expressed at three weeks of being unsupported ("nobody understands or cares.") It is likely that these were interrelated with marital ambivalence, and that all contributed together to poor outcome.

Of the multitude of predictive variables scrutinized in this study, Parkes regressed eighteen against measures of outcome. Six of these were found to be the most useful predictors of outcome in this young population sample. They were:

- (1) Presence of yearning at 3-4 weeks after the loss.
- (2) Attitude towards one's own death.
- (3) Duration of the terminal illness.
- (4) Social class.
- (5) Presence of anger at 3-4 weeks after the loss.
- (6) Presence of self-reproach 3-4 weeks after the loss.

Parkes mentions that these variables have been used with the family members of patients dying at St. Christopher's Hospice in London, to identify persons at high risk for poor outcome following bereavement. Intervention in such cases appears to reduce the long-term morbidity that would be expected to occur.

#### I.C.4 Outcome of Bereavement

In organizing this lengthy review and applying it to the present investigation, I will focus on possible outcomes. These can be subdivided into physical health, psychological and social health, use of habitual substances and medication, and help-seeking behavior. Wherever possible, I shall attempt to draw parallels between the morbidity associated with bereavement and morbidity that might be expected to occur during the terminal illness. Potentially predictive mediating variables explored by these and other studies are listed below (Section II.B.) These will not be discussed extensively in this section.

Parkes (1970) summarized data on self-assessment of general health in uncontrolled studies of the bereaved, including Marris's 1958 study. Most assess about 40% ill or deteriorated health. Parkes cautions on the interpretation of these incidences; in his group of 22 London widows, self-assessment of poor health was significantly associated with assessment by the interviewer of anger and irritability at the time of the interview.

Using their weighted scoring system, Maddison and Viola (1968) found that 21.2% of Boston widows and 32.1% of Sidney widows had marked health deterioration. Data about medical consultation and hospitalization for somatic problems is not given, though this was figured into the health score calculation. The sample of Clayton (1974) was probably quite different. Despite the fact that 83% of her subjects chose to see physicians and 83% had been hospitalized, only 10% admitted to general poor health over the year following bereavement. None of these values were increased above controls. Parkes and Brown (1972) also note no significant difference in general physical health between the 68 bereaved and controls in their Harvard study; the incidence for consultation and hospitalization

is much smaller. Excluding Clayton's study, which includes an older cohort, there appears to be between 20% and 40% incidence of poor or deteriorated health in the recently bereaved. This compared favorably with Ward's (1974) more objective data from general practitioners' assessment of 40% fair or poor health in the spouses of the terminally ill.

Rates of psychiatric symptomatology noted in the prospective studies were high, but rates of depression requiring treatment or hospitalization were low. 12.8% of Maddison and Viola's (1968) cohort had depression requiring treatment, but only 1.2% required hospitalization. Only 3 (3.3%) of Clayton's 90 St. Louis cohort (1974) consulted psychiatrists, and only one required hospitalization. Parkes and Brown (1972) also show comparably low percentages. These low rates, coupled with data showing that bereaved 40-65 years old differ little from nonbereaved of the same age on indices of neuroticism (Crisp and Priest, 1972), suggest that serious psychiatric illness among the bereaved is uncommon.

Symptomatology is analyzed with detail in the studies of Maddison and Viola (1968) and Clayton (1974). Symptoms commonly present in the bereaved and significantly more frequent than in the control groups are listed in Table III. Strictly speaking, the two lists are not comparable. Maddison and Viola sought symptoms that had started or worsened over the year following bereavement, while Clayton asked for symptoms that had been experienced at any time during the year. The former authors emphasized somatic symptoms, while the latter emphasized psychological symptoms. Retrospective distortion could have lowered the percentages noted in the former study even further; subjects whose symptoms--particularly psychological symptoms--had abated would have been less likely to recall temporary worsening of those symptoms. Also con-

**TABLE III**  
**SYMPTOMATOLOGY IN THE FIRST YEAR OF BEREAVEMENT**

Symptom	Maddison and Viola (1968) % experiencing new or more troublesome symptom N=375	Clayton (1974) % experiencing symptom N=90
<u>Neuropsychiatric</u>		
Depression/depressed mood	22.7*	90*
Crying		97*
Sleep disturbance	40.8*	81*
Nightmares	8.8*	
Difficulty concentrating		35*
Speed of thinking decreased		35*
Loss of interest		49*
Feels memory poor		49*
Feels worthless		13
Feels guilty		27*
Feels life hopeless		19*
General nervousness	41.3*	
Restlessness		35
"Fear of nervous breakdown"	13.1*	2
Feelings of panic	12.0*	
Anxiety attacks		13
Persistent fears	12.0*	
Irritability		25
Repeated peculiar thoughts	8.5*	
Hallucinations		12*
Wish dead		18*
Suicidal thoughts		3
<u>Neurological</u>		
Fainting spells	1.3*	3
Trembling	10.4*	
<u>General somatic</u>		
Frequent infection	2.1*	
Reduced work capacity	46.7*	
Fatigue	29.6*	55*
Weight gain	8.5	
Weight loss	13.6*	50*
<u>Dermatological</u>		
Skin rashes	6.1*	
Excessive sweating	9.3*	9

\*Incidence is significantly greater than that for controls in the study, by Chi-Square analysis with 1 degree of freedom.

TABLE III (continued)

Symptom	Maddison and Viola (1968) %experiencing new or more troublesome symptom N = 375	Clayton (1974) % experiencing symptom N=90
<u>HEENT</u>		
Headache	17.6*	31
Migraine	4.8	
Dizziness	9.1*	17
Facial pain	1.9	
Blurred vision	13.7*	25*
Difficulty swallowing	4.8*	
<u>Cardiorespiratory</u>		
Palpitations	12.5*	17*
Chest pain	10.1*	17
Dyspnea	12.0*	28*
Asthma	2.4	
<u>Gastrointestinal</u>		
Indigestion	9.9*	
Abdominal pain		21
Peptic ulceration	2.1	
Vomiting	2.7*	6
Excessive appetite	5.4*	
Anorexia	13.1*	51*
Constipation		33
<u>Genitourinary</u>		
Menorrhagia	3.4*	
Urinary frequency		31
<u>Locomotor</u>		
General aching	8.4*	
Back or joint pain		51

\*Incidence is significantly greater than that for controls in the study, by Chi-Square analysis with 1 degree of freedom.

tributing to the disparity between the studies is the probable greater sensitivity of Clayton's interview techniques, as compared with the self-report postal questionnaire. Overall, however, the characteristics of the symptoms listed are similar. The major symptoms of grief noted in many other studies appear in both lists. It is likely that any or all of these symptoms would appear prior to death in family members undergoing anticipatory grief.

Changes in the use of medication, tobacco, and alcohol were discussed in the prospective studies. Maddison and Viola (1968) noted that about a third of the bereaved increased their drug intake. 5.9% had marked increase in their intake. 6.7% increased their use of alcohol, and 11.7% markedly increased their smoking. All of these were significantly greater than control values. Of Clayton's (1974) sample, 51% admitted to taking medicine for general health, while about a third admitted to taking each of tranquilizers and sleep medicine. Only the use of sleep medicine was significantly increased above controls. Of the 109 original subjects interviewed one month after bereavement, 10 (9%) had been heavy drinkers, while only 4 of these (4% of total cohort) increased their drinking after bereavement (Clayton and associates, 1971). Parkes and Brown (1972) showed that 28% of their sample smoked more and the same percentage consumed more alcohol over the year following bereavement. 26% had started taking tranquilizers. All three of these were significantly increased above controls. 22% started taking drugs for sleep, but this was not significantly different from such use in the control group.

The difference in significance in the use of sleep medicine between Clayton's (1974) and Parkes and Brown's (1972) studies is unexplained.

It's possible that the age discrepancy between the study samples could have something to do with the observed findings. Comparing younger and older subjects in their cohort at one month, though, Clayton and associates (1971) found little difference in either insomnia or the use of sleep medicines. 27 (40%) of Parkes and Brown's cohort complained of problems waking up in the middle of sleep, but the overall incidence of sleep disturbance is not specified. Clayton's high incidence of 81% differs little from that of several studies of younger cohorts (Marris, 1958; Yamamoto and associates, 1969). There is a small amount of evidence that younger widows require prescriptions of sedatives or hypnotics (not differentiated in the study) more frequently following bereavement than older widows (Parkes, 1964a). Only one study has demonstrated that older bereaved are more frequently and more significantly affected in this way following bereavement. In this study (Wiener and associates, 1975), preliminary results show that the incidence of use of medication (class of drug not specified) five to eight months following bereavement is higher in older than younger bereaved, and also significantly greater than controls for older but not younger bereaved.

Cultural and religious characteristics of cohorts could account for some of the differences in use of drugs and alcohol between the studies. These are explored in Maddison and Viola's study. Australian widows tended to make more use of drugs following bereavement, while American widows tended to use alcohol more frequently. Slightly more than half of both Clayton's cohort and Maddison and Viola's Australian widows were Protestant. Parkes and Brown's cohort, on the other hand, was largely Irish or Italian Roman Catholic, and only 18% Protestant. Maddison and Viola's Boston sample was selected from the same population as

Parkes and Brown's, and was only 25% Protestant. The ethnic and religious difference noted in Maddison and Viola's study samples could account in part for the higher frequency of increased alcohol use in Parkes and Brown's than Clayton's bereaved cohorts. Unfortunately, Clayton (1974) does not offer an incidence of increased alcohol consumption for the full year following bereavement, so the incidence elicited at one month (Clayton and associates, 1971) is not strictly comparable to that from the other studies.

Despite differences, though, the studies suggest that a substantial number of bereaved persons tend to increase their use of drugs and habitual substances during the period of their grief.

If the "depressive symptom complex" of Clayton and associates (1972, 1973) or some other kind of anticipatory reaction were to occur prior to death, one might expect that the same kind of symptomatology, change in health, increased use of habitual substances, need for medication, and risk of illness might occur. However, there is a small amount of evidence to the contrary. In their 1968 study, Clayton and associates noted that most of the 22 subjects (55% of bereaved) who admitted to alcoholic consumption after bereavement had cut down their consumption during the illness or at least maintained it at the same level. It's possible that the social stigmatizing effects of alcoholic consumption might work to prevent indulgence in this habit while the ill spouse is alive. One doesn't know the amount consumed by Clayton's subjects, though. Parkes and Brown (1972) noted that roughly the same percentage of bereaved and controls (25% vs. 21%) admitted to drinking to excess during the prior year, but did not question subjects about consumption before the death.



The same may or may not be true of intake of medication during the terminal illness. Use of medicine would depend upon symptomatology experienced and upon medical help-seeking behavior, through which medication would be prescribed or obtained.

Studies of help-seeking following bereavement show mixed results. Parkes (1964a) medical records study demonstrated a marked increase in physicians visits after bereavement for widows under 65, compared with prebereavement rates. Cartwright and associates (1973) showed that 51% of their large sample visited physicians after bereavement, there is no control group, though, for comparison. Parkes and Brown (1972) noted that a significantly higher percentage of widows than female controls sought professional help for emotional problems, but no increase above controls was noted for medical consultations. Only one recent controlled study demonstrated increased consultation rates for medical problems above control rates (Wiener and associates, 1975). Preliminary reports from this study showed more frequent consultations for widows over 60 years old.

Parkes (1970) suggested that the inclination to visit a doctor may have been affected by the relative drop in income suffered by the bereaved and the lack of national health insurance to pay for office visits. Maddison and Viola offer evidence to support this. There was significant difference in health deterioration scores between Boston and Sidney bereaved. The fact that national health insurance exists in Sidney could have been associated with an increased tendency to utilize physicians' services. By their weighting system, this would have contributed to the higher percentages in the Australian bereaved of marked health deterioration. In contrast, the Boston widows in Parkes

and Brown's and Maddison and Viola's studies and Clayton's St. Louis studies lacked such a system, and the subjects probably had to pay for each office visit. It is impossible to comment on this definitely without knowing the insurance coverage for the subjects, but the high cost of physician consultation may influence whether or not the family member of the terminally ill seeks help from a physician.

Parkes' medical records study (1964a) offers some direct observations about physician consultation rates during the terminal illness, and raises other issues that could affect the help-seeking of the family members of the sick patient. He chose not to include the six month period prior to death as part of the control period, because of concern that illness in the husband would have influenced the consultation rate of the wife. As it turned out, for widows under 65 years old there was no difference in consultation rates between that time period and the one before. For widows 65 or older the number of consultations for both psychiatric and non-psychiatric symptoms actually decreased during that period. Parkes surmised that widows may have had difficulties seeing their physicians during the husband's last illness, or that preoccupation with the dying husband may have taken their minds off their own problems. Neither of these is specified further, and no attempt is made to characterize which widows might have increased or decreased their consultations prior to their husband's deaths. If the terminal illness and responsibilities assumed by the family member should become severe and all-consuming, it is likely that the normal patterns of seeking help would be altered.

## I.D. Other Applicable Studies

### I.D.1. The Burden of Caring for the Chronically or Terminally Ill.

The strain on relatives of maintaining an elderly or chronically ill family member at home can be quite severe. Hackett (1976) lists five common complaints of the dying patient: pain, dyspnea, nausea, loneliness, and fear of suffering. Hampe (1975) and Freihofer and Felton (1976) have pointed out the importance to the family of the patient's comfort. If the complaints of the terminally ill person aren't properly managed, the result can be strain and burden on the family that can interfere with the anticipatory processes needed to work towards acceptance of impending death. Three studies that look at the patient's illness and how it affects the family are presented in this section.

Family strain is a frequent primary cause for admission of the sick person to a hospital or institution. Isaacs (1971) explored the reasons for admission to a geriatric unit for 280 Glasgow patients. Strain on the household was evident in half of the cases, and 32% of patients were admitted specifically because of it. "Strain" involved any threat to the physical and mental health of the family members. In nearly all of these cases, responsibility for home care fell on one person--the primary "helper"--usually one of the patient's children. Characteristics of patients and their disease processes associated with strain included increased frequency of incontinence, irritability, mental abnormality, and prolonged illness. These patients were generally sicker and had higher subsequent mortality. Strained helpers tended to be older with 72% aged 50 years or more. Factors in the living space that contributed to strain included competing demands on time and energy, care of young children, presence of other sick relatives, and the need

to surrender employment, leisure interests, and all normal social life. Some of the most stressful problems identified by the helpers were the tendency for the patient to fall (and hence require constant attention), excessive exploitation of the helper, and excessive demands made upon the helper.

Cartwright, Hockey, and Anderson (1973, pp. 143-162) identified 74% of 303 spouses of the deceased in their sample as having assumed major responsibility for care of the patient during the terminal illness. They called these people "brunt bearers." About 20% of these felt they had been under strain, and about 14% said that looking after the deceased had adversely affected their health. The responsibilities assumed by the spouses were quite substantial and included all aspects of basic nursing care. The specific factors contributing to strain were not enumerated, though 71% of spouses had to deal with at least one symptom that was very distressing to the patient. Symptoms occurring in a substantial number of patients (more than 20%), frequently reported as distressful included pain, sleeplessness, loss of bladder and bowel control, vomiting, loss of appetite, constipation, mental confusion, trouble breathing, and depression (p. 21). In general, the larger the number of symptoms and the number of things needed help with, the greater the number of helpers (friends or relatives) who were needed to keep the patient at home. In addition, the longer the illness, the more likely the family was to receive infrequent visits from district nurses (p.105), placing the burden more heavily upon other helpers. It is possible that this decrease in professional support may have reflected better adjustment to the illness or lack of severity of the longer illnesses.

More definitive psychological evidence for strain comes from an earlier study. Klein, Dean, and Brogdonoff (1967) examined symptoms of psychological and interpersonal distress in 73 spouses of patients 21-55 years old, applying for care at a university hospital outpatient department. The patients had all been sick for more than six months at the time of the study. Subjects were largely lower to low-middle class, male (63%); and white (80%); the education level averaged 8 years; and the type of employment was usually unskilled or semi-skilled work. Persons with problems of alcoholism, other addiction, or psychosis, and persons already receiving professional support were excluded. Subjects and patients were administered questionnaires covering general activities, and symptoms of both psychophysiologic distress and interpersonal role tension. These were asked in relation to time periods before and during the illness. Subjects were also asked to report the symptoms they perceived as occurring in the patient.

Results showed a significant change in symptoms and tension associated with the illness. 67% of subjects reported an increase in symptom levels during the illness period. Specific symptoms frequently reported to increase during this time were: fatigue (23%), general weakness (14%), inability to get going (16%), and nervousness (23%). Symptoms suggestive of role tension reported to increase included jumpiness (19%), tendency to be easily depressed (14%), tendency to be easily excited (18%), and tendency to hide feelings (14%). There were significant positive correlations between the subjects' symptoms of psychophysiologic distress and role tension, and between the subjects' role tension and their reports of the patients' psychophysiologic symptoms. Reduction of the patient's activity was associated with reduction of the spouse's activity, implying

that as the patient's illness becomes more restrictive, the activity enjoyed by the spouse becomes more restricted.

The authors suggest several possible explanations for the high correlations among psychophysiologic symptoms, role tensions, and report of the patient's symptoms. Increasing symptomatology in either the spouse or the patient could cause increased role tension. Conversely, greater role tension could cause increased perceptibility of symptoms. The level of tension and symptoms was sometimes higher in the spouses than in the patients. This would imply that some of the spouses were as symptomatic and as much in need of attention as the patients seeking treatment. It's possible that within the family structure, it was possible for only one and not both to assume illness behavior or sick role behavior without considerable social conflict. The result was that one member (the patient) had a recognized illness and was receiving both medical treatment and care from the spouse, while the spouse received little of either. The result was role tension and strain. The authors equate such strain with role failure, but that is debatable. The seeking of help at the medical center and development of symptomatology probably represented efforts to maintain the stability of existing roles, as precarious as they were. No mention is made of phenomena indicative of total failure to cope or social disintegration (Meissner, 1977).

These studies have shown, then, an interrelationship between severity of the patient's illness, strain on the family member expressed by symptomatology and role tension, and the need for extra help or hospitalization to care for the patient. As the illness worsens, the strain and its effects can become even more severe. In the early stages of the disease, the home environment can be redesigned or rearranged to suit the needs of the sick person, and other helpers can be brought in to

take some of the minor responsibilities. As the disease progresses, however, the burdens become greater and more difficult to coordinate, finally requiring that one person take major responsibility. If outside help is unavailable, strain is likely to develop at this point.

Adding to this can be interpersonal dilemmas and personality difficulties mentioned by Isaacs (1971) and Cartwright and associates (1973). The dying may have particular needs for closeness, warmth, and attention (Kubler-Ross, 1969). In the terminal phase of the disease, these needs coupled with the increasing burdens of comfort care from the worsening illness can create a situation of entrapment of the close family member, usually the spouse (Strauss, 1975). The intimate family member may be virtually trapped at the bedside by the patient for hours or days or longer. This can end only when the patient loses consciousness or dies or the family member breaks down. Under such circumstances, one would expect the stress with its accompanying symptomatology and toll on health to be severe. The seeking of help at such time would, however, be virtually impossible.

## I.D. 2 The Patient's Adjustment to Terminal Illness

The phenomenon of anticipatory grief is well known to occur in the dying patient. Kubler-Ross (1969) has described five psychological stages of "dying" which many terminally ill patients go through. They are: denial, anger, bargaining, depression, and acceptance. During these stages, particularly the stage of depression, the patient may grieve for his own anticipated losses. If allowed to progress to completion, this grief process can facilitate greater acceptance of impending death (Kubler-Ross, 1969, 1975; Hinton, 1972; Wilkes, 1975; and many others). It is common for the reaction of the family to parallel that of the patient (Heimlich and Kutscher, 1970). If such anticipatory grief processes are coordinated between family and patient, both can move towards acceptance of death together (Parkes, 1972, pp. 128-132).

The dying patient and his/her family share a common psychosocial milieu, especially if the patient is cared for at home. Analysis of problems faced by the patient may therefore help to elucidate potential difficulties faced by the family. It is beyond the scope of this paper to delve deeply into intrapsychic and psychotherapeutic problems of the dying patient. Analysis of psychosocial and physical factors affecting the patient's adjustment to dying, though, are of practical importance to this study. One investigation in particular attempted to explore this systematically.

As part of a pastoral counseling program in an Illinois hospital, Carey (1975) interviewed 84 terminally ill patients of all ages. He found that poor emotional adjustment in these patients was associated with a high level of physical discomfort and with prior close contact with someone terminally ill who had been angry and upset about it. Prior



contact with someone who had been able to accept death with inner peace was associated with a good adjustment. For women, those who had previously discussed death openly and frankly with another dying person were better adjusted. Other factors positively associated with emotional adjustment include intrinsic religious orientation, Christian (vs. non-Christian) religious practice, level of education, and financial security. Intrinsic religious orientation involves the individual's integration of religious principles with his/her lifestyle; this contrasts with extrinsic orientation, in which the individual ascribes his beliefs to a theological system completely outside of himself.

It is likely that many, if not most of these would affect the family in the same ways. Religious orientation, religious practice, prior experiences with terminally ill relatives, and financial security are all factors that would tend to be shared among patient and family. The first three of these could affect the family's capacity to accept the fact of terminal illness and adjust to it. Physical pain and discomfort in the patient might markedly affect the family's emotional adjustment. This is evidenced by studies of the effects of chronic illness on the family (Klein and associates, 1967; Isaacs, 1971; Cartwright and associates, 1973).

### I.D. 3 Coping with the Unknown Regarding a Significant Family Member

An important aspect of terminal illness not yet discussed is the question of uncertainty regarding length of life. One never knows absolutely when death will occur. Medical and lay literature are replete with documented cases of unexpected cures and remissions of patients all but given up as lost (Boyd, 1966). At the same time, the spector of endless, prolonged deterioration haunts the minds of many patients and families. The strain on the family members when the status of the loved one is unknown is illustrated by a study that took place in Israel during the Middle Eastern War of 1973. Though the situation of soldiers missing in action is extreme, this study offers information of use to the current investigation.

Teichman (1975) studied the reactions of 20 Israeli families to their family member being declared missing in action. (MIA). Three basic behavioral patterns were noted in response to the stress of possible imminent loss:

(1) Defensive resignation. The families prepared themselves for the worst, gave up hope, referred to their relative in the past tense, and began grieving at a socially acceptable level.

(2) Defensive optimism. The families expressed denial and accumulated selective, often biased, ambiguous information to support their views.

(3) Search for objective information. The families organized themselves and everyone around them to seek objective data about the MIA's.

The first of these suggests predominance of affective grief response in a setting of hopelessness while the latter two show predominance

of active searching. The first two responses have a high degree of denial, while the third does not. Teichman noted that grief responses to actual death tended to be much more severe and prolonged in individuals responding in the first two ways than in the last. Thus the presence of an anticipatory affective grief response or the presence of marked denial was associated with poorer outcome after bereavement.

Teichman also examined the reactions of individual family members to the impending loss. Parents behaved in predominantly three ways. Some expressed personal grief with temporary social withdrawal, general disorganization, and personal neglect. Some reacted with public suppression of any grief responses; this fit the social norms of "being strong" and acting "heroic" during the war crisis. Others reacted with bitterness, hostility, and criticism. In some cases the bitterness persisted, resulting in feelings of guilt and shame.

Unique to wives were dependent behavior and preoccupation with practical daily matters. Some wives were unable to do anything or make any decisions whatsoever without assistance. Such problems with dependency were perpetuated when well-meaning relatives and friends took over all responsibilities. The preoccupation of other wives with practical, often trivial matters served to prevent the facing of fear and anxiety. Like many of the parents, other wives also reacted with bitterness and heroism.

Children seemed to react more to stress in the home environment than to the loss, per se. Various behavior problems were noted. Mothers tended to overprotect and avoid or postpone communication with their children about the loss. Intermittent resumption of normal activity was particularly bothersome to distraught or grieving mothers

and was a source of potential serious conflict. Denial and identification with the behavior of the father were looked upon as more serious; fortunately, they were rare.

Social responses in neighbors, friends, and the general community varied. There was social pressure to accept the cultural norms of a "Heroic" appearance, with little or no affective response. For those able to adopt this stance honestly and sincerely, the community could be a source of support. When affective response had to be suppressed to live up to this standard, though, the community tended to add to the tension. At the start of the crisis, community support was usually strong, but as time progressed, social avoidance and isolation by the community tended to develop.

Where defensive denial dominated the reaction process, little could be done to change the response. On the other hand, intervention aimed at facilitating open flow of information, communicating a sense of confidence in a person's ability to cope adequately, and enlisting community support when needed did help considerably.

Reaction to the unknown in this study has several important differences from the reaction to terminal illness. First, as these people were probably all young, healthy, and highly involved with their families, the grief potential (Fulton and Fulton, 1972) here was very high. Their loss or threatened loss would likely evoke a very intense acute response. In contrast, many terminally ill patients would tend to have a trajectory of deterioration offering more opportunity for gradual adjustment to loss, withdrawal from the family, and possibly milder anticipatory reaction. Second, the missing person was completely inaccessible and unreachable. This could occur in some terminal illnesses, particularly where there is sudden neurologic deterioration and loss of the ability to

communicate, but in most cases it would not occur until the disease process were far advanced. If the terminally ill person were communicative, then one would expect not to see the searching behavior that dominated two of the three general response patterns Teichman described. Third, for families of the healthy MIA's, death must have been very difficult to imagine. For the family of the terminally ill person who is deteriorating, death is nearer, more an eventual certainty, and probably harder to deny. It would probably be more difficult to maintain defensive optimism, though that certainly happens.

Nevertheless, there are important similarities between this study and the present investigation. In both cases, the fact of impending loss, though indefinite, is an ever present possibility. The general reactions of individuals have been observed and described in the families of the terminally ill. If the family completes its grief process prior to the patient dying, the result can be similar to defensive resignation; it is as if the patient really is dead to them. Attempts to deny the loss are common among the bereaved; in the families of the terminally ill such behavior can take the form of not believing health professionals and seeking a physician or healer who will say the patient is not dying. Searching for objective information is common among the families of the terminally ill, though the role of the physician as provider of such objectivity would tend to mitigate such behavior. The reactions of social withdrawal, disorganization, suppression of the grief response, bitterness, preoccupation with practical matters, dependent behavior, and idiosyncratic reactions of children have all been described in the bereaved. Many have also been described in the families of the terminally ill. The social responses from friends, relatives, and the general

community, and the effects of community expectations upon the grief response all pertain. Many of these have been described by Maddison and Raphael (1972) and are summarized above (Section I.A.).

## II. Interactive Processes Affecting Morbidity

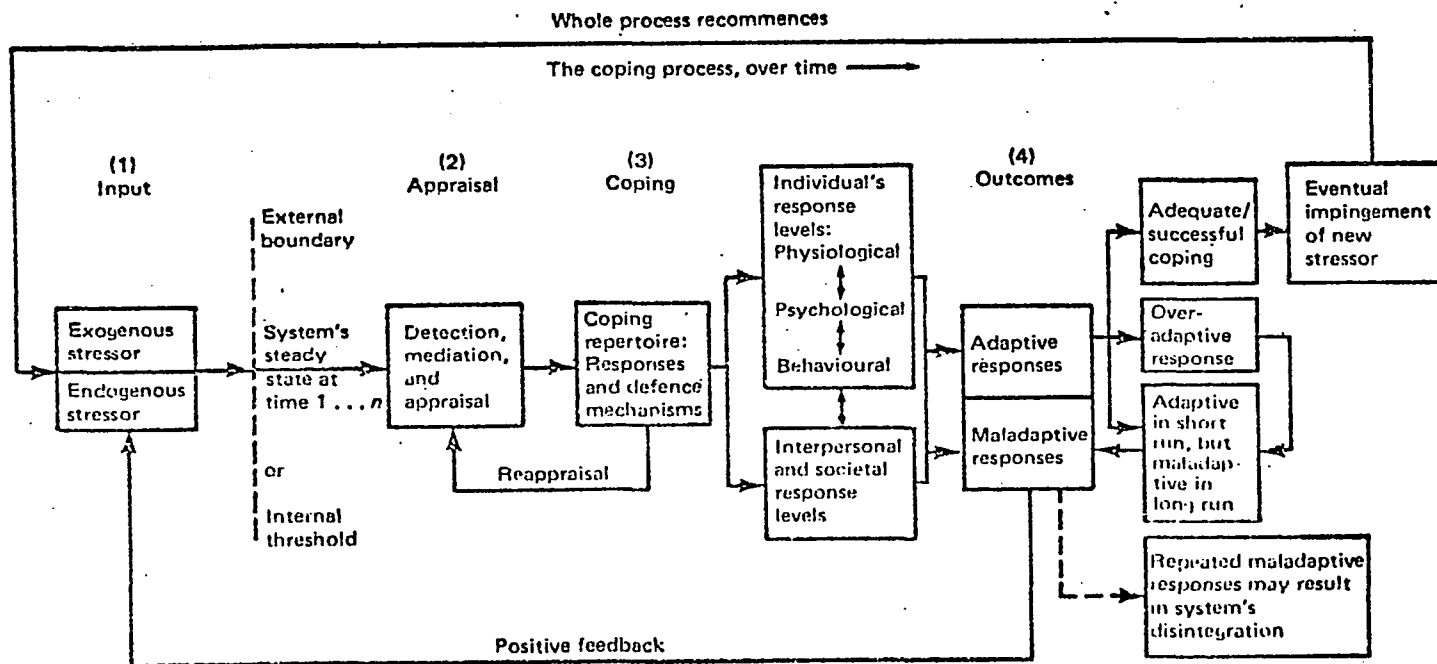
Many variables explored in the above studies have been shown to affect morbidity in various population samples studied. The present task is to organize in a useful manner those which are likely to affect the health of the family members of the terminally ill. To assist in this I will use a general model of stress. Lumsden (1975) has presented a general flow chart describing a paradigmatic model of an open system under stress. Developed for use with anthropologic systems, it is applicable to biologic systems at any level. It is dynamic, homeostatic, and self-regulating, and its parts are all interdependent. In this section I will briefly summarize Lumsden's thorough and well referenced presentation of the model. I will then use it to outline variables discussed in the studies abstracted above to apply to the families of the terminally ill.

### II.A. Presentation of Lumsden's Model of an Open System Under Stress

The model (Figure I ) consists of four basic sections: Input, Appraisal, Coping, and Outcome. As drawn, there is continual movement through these parts of the system with time.

Input involves contact of the system with a stressor. Lumsden defines a stressor as any stimulus which is a demand upon the system and its resources. Stressors can be exogenous or endogenous; exogenous stressors come from outside the system, while endogenous stressors are generated from within the system. A general example of an exogenous stressor is something done to a person by someone else. Examples of endogenous stressors are psychological or physical illnesses. The range of possible stressors is enormous.

Figure I



Paradigmatic flowchart of an open system under stress.

(Source: Lumsden, 1975, p. 194)



Appraisal involves several processes. Detection occurs when the stimulus to the system crosses a certain threshold or boundary. Whether or not the boundary or threshold is crossed depends on the characteristics of the stressor. These include its source, nature, duration, timing, intensity, frequency or rarity, ambiguity, novelty, meaning for the system, pleasantness/unpleasantness, avoidability/unavoidability, controllability, and predictability. Other factors influencing detection include previous experience of the system and history of successful/unsuccessful coping with the stressor, the interrelationship of the stressor with others that are affecting the system, and the aspects (part or all) of the system that are affected. Whether the stressor is endogenous or exogenous and whether or not the system gets feedback about how it is coping can both affect detection. It should be noted that some stressors are detected (and detectable) at one level of the system but not at others.

Factors affecting mediation and appraisal act between the stressor and the coping response and touch all intermediate processes. They include all characteristics about the system; for an individual person this includes demographic variables, general education and experience, general physical health, psychological health, personality characteristics and strengths, hereditary factors, and the complexity and flexibility of the coping repertoire. Factors on the social and family level affecting the individual include cultural values, the nature of family structure and functioning, prior family experience with stressors, social status and role of the individual, flexibility of response allowed by the group, and closeness of the individual to another person who is under stress. Whether or not the group is prepared for the stress

can affect the individual's responses to it.

Appraisal is a process that can take place on a conscious or unconscious level. The person's emotional response and responsiveness can affect appraisal of the stressor. This is also subject to influence by cultural norms and family group characteristics. Feedback from success or failure of coping responses can alter the appraisal of the stressor.

Coping consists of a repertoire of actions and behaviors available to a person to respond to the stressor. Many of the mediating factors already listed will influence the breadth and flexibility of the responses. Whether a specific response will be adaptive or maladaptive also depends on some of those factors. Information about the stressor and preparedness of the system can affect response. The intensity and severity of the stressor and the extent of coping resources are important but complex interacting variables. If the stressor is too intense or severe (overload), the system may not have the resources to respond as needed and the result may be maladaptive. If the stressor is too mild or small (underload), appraisal may be incorrect and the coping behavior inappropriate and also maladaptive. Information from feedback about coping responses can be utilized to alter coping responses to make them more energy efficient or successful.

Coping responses in an individual can occur on any level, from the physiologic to the interpersonal/societal. They can take the form of offensive or defensive physical action (example: fleeing), affective expression, psychological defense, health-seeking behavior, appetite-filling behavior, or even no response at all. All levels are mutually interactive. If coping on one level of the system does not work, then the system may respond on another level. An example which has been noted in

the studies of the bereaved is the development of psychosomatic symptomatology in place of emotional grief response.

Outcome responses may be adaptive or maladaptive. Coping which is adaptive on one level may be maladaptive on another. For example, as discussed already, the grief response may aid in the task of coming to terms with object loss, but it may also physiologically weaken the individual and set the stage for development of somatic disease. The result of adaptiveness of coping on one level but not others can be adaptive behavior in the short run, but maladaptive behavior in the long run. Another example to illustrate this is a person's coping with ongoing family or interpersonal stress while neglecting to care for his/her medical needs--an asymptomatic breast mass, for instance.

If coping is adaptive and successful, then the system is ready to accept the inevitable impingement of a new stressor, for which the process begins again. That stressor may be a continuation of the one successfully coped with. If so, the successful outcome will serve to dampen the demands made on the system by the stressor, or at least to maintain a steady state. Responses may be overadaptive or, as discussed above, adaptive in the short run, but not in the long run. Both of these are ultimately maladaptive on some level.

Maladaptive responses add to and amplify the demands on the system through positive feedback mechanisms. As such, they act as endogenous stressors. The resulting demands on the system increase until the system either detects the maladaptive aspect of the response and alters it adaptively or the system breaks down. Breakdown is exemplified by death on the organismic level and by social and family disintegration on the interpersonal level.

The nature of information handling by the system is crucial to applying it to the situation under study. Appraisal and reappraisal of stressors and the success or failure of coping allow the system to alter its responses appropriately. Similarly, inhibition of these processes--for example, by denial, avoidance, or anxiety--can lead to repeatedly maladaptive responses. Information from outside can enter the system along the same flow path as exogenous stressors. This information can then be used to appraise and reappraise stressor and coping responses, to facilitate corrective action that will dampen the maladaptive process.

## II.B Application of the Model: Outline of Interacting Variables

The variables that can be expected to affect the families of the terminally ill are many, varied, and complex. The following outline is not meant to be exhaustive. It is not possible to list and describe all variables; in its most liberal usage, the model could encompass almost every stimulus that affects the organism, and many of these are only marginally applicable to the situation at hand. Similarly, there are other ways of organizing the data that emphasize different aspects of the medicating variables and mechanisms of appraisal and coping. In this presentation variables are listed within particular sections of the model, but because all parts are interconnected and interdependent, all variables will affect all sections and all levels of the system in some way. To complete one's understanding of the model and its present application this must be kept in mind.

References are cited for several variables which are applicable to the outline but not discussed in the literature abstracted above.

### Outline of Variables Affecting the Families of the Terminally Ill

#### I. Input--stressor characteristics.

##### A. Exogenous stressors.

##### 1. Characteristics of the terminal illness.

- a. Length.
- b. Progression or trajectory.
- c. Presence of distressing symptomatology: pain, loss of bowel or bladder function, mental abnormality, and others.
- d. Presence of disease characteristics with special meaning to the family: loss of sexual function, and disfigurement.

2. Extent of burden of responsibility assumed.
  - a. Availability of other family members to help.
  - b. Availability of outside resources: visiting nurses, home health aids, hospitalization facilities, and efficient discharge planning where appropriate.
  - c. Accessibility to such resources.
  - d. Availability of support from extended family, friends, and neighbors.
  - e. Adequacy of finances.
  - f. Efficiency of organization of the home environment (Strauss, 1975).
  - g. Experience and skill of health professionals managing patient's care (skill in handling special problems of the dying) (Kubler-Ross, 1969).
3. Extent of restriction in social interaction and support.

- a. Loss of care and support from patient.
- b. Loss of outside support from decreased time and energy spent in social/leisure activities.

B. Endogenous stressors.

1. Anticipation of death and change.
2. Affective states associated with other stressors.
  - a. Anxiety/restlessness.
  - b. Depression/hopelessness.
  - c. Sense of failure.
  - d. Guilt.
  - e. Anger/hostility/resentment.
3. Somatic and psychosomatic illness and symptomatology.

II. Appraisal.

- A. Detection, appraisal, and reappraisal.
  1. Exogenous factors

- a. Stressor characteristics (listed above).
- b. Avoidability of stressor: presence of entrapment at bedside by patient.
- c. General level of environmental stimuli.
- d. Openness of communications feedback channels.
  - (1) With patient
  - (2) With other family members.
  - (3) With health or other professionals (Fulton and Fulton, 1972).

## 2. Endogenous factors

- a. Affective response states.
  - (1) Anxiety.
  - (2) Depression/hopelessness.
  - (3) Overall negative affect/sense of failure.
  - (4) Guilt.
  - (5) Perceived unhelpfulness of the environment.
  - (6) Anger/hostility/resentment.
- b. Religious belief/orientation.
- c. Capacity to accept affective states within self (Peretz, 1970a).
- d. Prior experience
  - (1) With similar kinds of stressors, particularly involving the dying.
  - (2) With other stressors.

## B. Mediation

- 1. Personal/demographic factors.
  - a. Sex.
  - b. Age.
  - c. Social class.

d. Level of education.

e. Employment status.

f. Ethnicity.

2. Somatic factors.

a. Presence of pre-existing illness.

b. Predisposition for development of disease (genetic or other risk factors).

c. General baseline perceptibility of bodily symptoms.

d. Past medical history.

e. Physiologic coping style (psychoendocrinologic pattern).

3. Psychological factors.

a. Early childhood separation experiences (Epstein and Associates, 1975).

b. Past bereavement of parents.

c. Disturbed relationship with parents.

d. Prior or current history of psychiatric illness.

e. Prior or current use of alcohol, sleep medicine, tranquilizers, and other drugs/habitual substances in reaction to stress.

f. Success of prior experiences coping with stress.

g. Personality characteristics.

h. Factors influencing perception of illness (Kasl and Cobb, 1966a).

(1) Importance of health to subject.

(2) Perceived susceptibility to disease.

4. Marital factors.

a. Intensity of prior and current involvement.

b. Presence of ambivalence.

c. Tendency towards identification with spouse.



d. Extent of dependence upon spouse.

5. Family system factors.

a. Role of patient in the family.

b. Role of the family member in the family system.

c. Presence of small children.

d. Success of prior experiences of the family coping with illness and stress.

e. Flexibility of roles of family members.

f. Openness of communication patterns in family.

6. Socio-cultural factors.

a. Social network characteristics.

b. Presence of social support.

(1) Extended family.

(2) Friends.

(3) Neighbors.

(4) Presence of confidant (e).

c. Perceived and actual helpfulness of social support.

d. Adherence to/participation in religious activities.

(1) Custom and tradition.

(2) Rituals, particularly pertaining to the dying and bereaved.

e. Prevailing attitudes towards death, dying, illness and health.

f. Social expectations relating to:

(1) Care of the sick and dying.

(2) Expression of affective distress and anticipatory grief by the patient and family members.

g. Medical care factors (Kasl and Cobb, 1966a).

(1) Cost of medical care--medical insurance.

(2) Past utilization of medical services.

(3) Attitudes towards health professionals.

### III. Coping.

#### A. Characteristics of coping repertoire.

##### 1. Physiologic/somatic.

a. Fight/flight reaction.

b. Conservation/withdrawal reaction.

c. Other or intermediate responses.

##### 2. Psychological.

a. Defensive responses (Maddison and Raphael, 1972).

(1) Denial.

(2) Isolation of affect.

(3) Sublimation.

(4) Repression.

(5) Displacement.

(6) Projection.

(7) Introjection.

b. Facility and flexibility of emotional expression.

3. Behavioral: defenses to maintain integrity of social and family supports.

#### B. Factors affecting energy and resources available to use for coping.

1. General health.

2. Presence of exhaustion (all energy used up from prior coping).

3. Presence of concurrent stresses or multiple life crises.

4. Access to outside resources, listed above.

### IV. Outcomes

#### A. Somatic responses.

1. Development of symptomatology or increased perceptiveness of symptomatology.
2. Development of somatic disease.
3. Alteration of psychophysiological state.
  - a. Fight/flight: heightened arousal.
  - b. Conservation/withdrawal: possibly reduced arousal.

B. Psychologic responses.

1. Development of grief anticipatory grief reaction.
2. Development of affective states.
  - a. Anxiety.
  - b. Depression.
  - c. Overall negative affect.
  - d. Guilt/self-reproach.
  - e. Anger/resentment/hostility.
  - f. Sense of greater acceptance of terminal illness.
  - g. Attribution of meaning of terminal illness and death.
3. Suppression of affective response.
4. Emotional disengagement.

C. Behavioral responses.

1. Adaptive behaviors (probably adaptive).
  - a. Increase of the amount and intensity of activity necessary to care for the patient adequately.
  - b. Acceptance of help and support offered.
  - c. Enlistment of social support and resources.
  - d. Surrender of social/leisure activities.
2. Maladaptive behaviors (probably maladaptive).
  - a. Overactivity and preoccupation with trivial, practical matters.

- b. Impulsive acting-out or sociopathic behavior.
- c. Avoidance of the patient.
- d. Avoidance of the family member's own needs.
- e. Indulgence in the use of alcohol, other habitual substances, or medications.
- f. Sick role behavior.

### III, Methods

#### III.A. Data Gathering Instruments

The questionnaire which appears in Appendix II consists of several data gathering instruments:

1. Data Sheets (about subject).
2. Recent Life Change Scale.
3. Psychological Assessment Scales.
4. Health Survey.
5. Data Sheet Regarding Spouse.

It is given to the subject to fill out in four stapled sections, the first section corresponding to instruments #1 and #2, and the second, third, and fourth corresponding to #3, #4, and #5. The data gathering instruments are designed (1) to elicit evidence of psychiatric or somatic morbidity, associated with the time period of the spouse's serious or terminal illness, which warrants attention, (2) to elucidate from whom the subject has been seeking help during that time period, and (3) to characterize those subjects with morbidity who are not seeking help for it.

##### 1. Data Sheets (pp. 1-6).

The purpose of this section is to gather general demographic, socioeconomic, and social information about the subject. Also included are questions about general health and accessibility to physician's services. Except where specified, items are forced-choice, with only one answer being acceptable per item. For convenience and speed, responses are structured so that the subject need only make a check mark next to his/her choice.

a. Demographic Variables

Sex (Question #1).

Age (Question #2).

Racial Group (Question #3).

Occupation, Education, and Social Class (Questions #4, #5).

Occupation is basically a seven-point scale with two added points, one for unemployment or no previous job skill and the other for housewife/house-husband, an occupation which may require considerable skill but does not fit under any of the other categories, per se. This scale, as well as the seven-point education scale are derived from Hollingshead (1957) and used to calculate scores of socioeconomic status and social class.

The score of socioeconomic status is calculated by the following formula:

$$\text{SES Score} = (\text{Occupation Level}) \times 7 + (\text{Education Level}) \times 4$$

Social class in this system is defined by certain limits established by Hollingshead, based on the SES score, as follows:

<u>Social Class</u>	<u>SES Score Limits</u>
I	11-17
II	18-27
III	28-43
IV	44-66
V	61-77

In Hollingshead's original use of the two-factor index, the SES score and social class for an individual were defined by the education level and occupation for the head of the household. Applying his criteria to the present study, several problems arise. First, who is the head of the

household? If the breadwinner is terminally ill, and the subject cannot work, problems of definition exist. Second, how should retired individuals, or the skilled unemployed be treated? To this author's knowledge, these questions have not been adequately addressed.

In this study, the two factor index and social class are used for both husband and wife. If the individual is retired, the occupation prior to retirement is used. If the person is skilled but unemployed, the potential occupation level is used. In the case of a housewife, if she has worked in the past, that occupation is used. If not, she is treated as if unskilled. Thus, social class as measured for each individual may reflect a past status that is no longer valid.

Employment Status (Question #6). This is designed to complement occupation in Question #4, and to provide information about the extent of present employment.

Ethnicity (Question #7). This reflects the breakdown of major ethnic groups in America and is applicable to New Haven and vicinity.

Religion (Question #8). The category of "none" is present to identify individuals who do not have the support of a religious group or tradition.

Religiousness (Question #9). This is a measure of frequency of religious observance and participation. It has an eight-point scale ranging from "never" to "daily." Note that this does not represent the quality of religious belief or religious orientation.

#### b. Social Variables

Family Size and Dependents (Question #10). This has three parts: the total number who live in the household, the number of children under 16 years old, and the number of older dependents. Only the first of

these include the patient.

Perceived Nearness of Relatives (Question #11). This measure perceived proximity to relatives, and is a crude measure of accessibility to support from the extended family. It is expected that many relatives living nearby would constitute a more accessible extended family group than if all relatives lived far away. No specific criteria for "few," "many," "nearby," or "far away" are stipulated; what they mean may vary widely from one subject to another. It is expected, however, that the subjective assessment of relative number and proximity of relatives by each subject would be a more accurate reflection of accessibility than any external arbitrarily set criteria.

Frequency of Contact with Relatives (Question #12). This has the same eight point scale as question #9.

Perceived Nearness to Close Friends (Question #13). This is treated exactly as relatives are in Question #11.

Frequency of Contact with Relatives (Question #14). This is treated exactly as relatives are in Question #12.

Presence of Confidant(e) (Question #15). This is an indication of whether or not the subject has one or more persons with whom he/she can share feelings.

Frequency of Social Activities (Question #16). As a general indicator of the level of social activity, inside or outside the home, this index has a six-point scale ranging from "never" to "daily." It is similar to that for Question #9, except that two of the more infrequent choices are deleted.

Frequency of Accompaniment by Spouse in Social Activities (Question #17). The purpose of this variable is to assess relative



independence from the spouse in social activities. It has a five point scale, ranging from "always" to "never." If the spouse always accompanies the subject, then it is assumed that the subject is relatively dependent upon the spouse for social activities.

c. Transportation Data

Mode of Transportation (Question #18). More than one choice can be selected here. The choice "Friend's car" is expanded to include a relative's car as well.

Proportion of Time Subject Drives (Question #19). This is a crude measure of the dependence on others for driving, if the subject uses a car. The assumption made is that if the subject never drives, even if able, then he/she is more dependent on others for transportation by automobile. A four-point scale is used, with a fifth choice for those who do not drive.

Difficulty Getting Around Town (Question #20). This uses a five-point scale to measure the proportion of time the subject perceives transporting himself locally as difficult. The scale is exactly the reverse of the scale used in question #17. What constitutes "difficult," "getting around town," or the presence of travelling or transporting are not specified and may vary considerably from subject to subject. However, the fact that the process is perceived as difficult implies that it requires more work and energy and is more trying to the subject than if it were easy. The proportion of time it is difficult measures overall strain on the subject from this activity.

d. Financial Data

Family Income (Question #21).

Change in Financial Situation (Question #22). This is a five-point scale varying from "much worse" to "much better." The financial situation at present is compared with the situation before the spouse became ill.

Recent Adequacy of Finances (Question #23). This is taken from Weissman's Social Adjustment Self-report Questionnaire (Weissman and Bothwell, 1976), and measures the ability of the subject to take care of his/her own and his/her family's financial needs during the prior two weeks.

e. General Health

Perceived Current State of Health (Question #24). This is a four-point scale ranging from "Excellent" to "Poor."

Perceived Change of Health (Question #25). The change is assessed by a five-point scale ranging from "It's gotten much worse" to "It's gotten much better." The time period for this change is the length of the spouse's illness.

Weight Gain or Loss (Question #26).

f. Data about the Subject's Doctor

In this section, information is asked relating to the subject's personal physician, identified as "your doctor" in the text of the questions and responses. In cases where more than one doctor was identified, the one to whom the subject brings his own personal health needs is used.

Specialty (Question #27).

Difficulty of Travel to Doctor's Office (Question #28). This has a three-point scale, from "Very hard to get there" to "Easy to get there."

Difficulty of Contacting Doctor (Question #29). This is a measure of accessibility to the physician, using a four-point scale from "Always very easy" to "Always very hard."

Affiliation of Doctor with Hospice (Question #30). Answered yes or no.

Equivalence of Subject's and Spouse's Doctor (Question #31). Answered yes/no.

g. Health Insurance Data.

Health Insurance Coverage (Question #32). The subject is asked to check any of four basic medical costs covered by his/her insurance. These include inpatient costs, emergency coverage, outpatient clinic visits, and private doctor's office visits.

h. Contact with Hospice Staff.

Overall Frequency of Contact (Question #33). Using a six-point scale, this measures the frequency of contact (at any time) with Hospice Staff. Responses range from "Several times a year or less" to "Daily."

Frequency of Contact Concerning Subject's Own Needs (Question #34). Using the same six-point scale, the frequency of contact involving the subject's personal needs is measured.

i. Help-seeking Behavior.

Frequency of Contact (Question #35). In this section the subject is asked to indicate the categories of professionals from whom he has received help. The time reference is the length of the spouse's illness. The categories of professionals are the following:

"Your personal or family physician."

"Another doctor or specialist."

"Psychiatrist or psychologist."

"Social worker, nurse, or other health worker."

"Minister or religious counselor."

"Other" (the subject may fill in).

The length of the spouse's illness is used as the time reference. A five-point frequency scale, ranging from "I never contact" to "More than monthly" is applied to each category.

Perceived Helpfulness (Question #36). The subject is asked to rate the past or present helpfulness of each type of professional he/she has had contact with. The same categories of professionals as in question #35 are used.

## 2. Recent Life Change Scale (Page 7).

This is a 35-item survey instrument based on the 43-item Social Readjustment Rating Scale of Holmes and Rahe (1967). Each of the original scale items has been assigned a score of from 11 to 100 "Life Change Units" (LCU). Scoring was based on the responses of population samples who were asked to compare the "amount" of change of each item with that of marriage, which was assigned an arbitrary score of 500. For practical purposes the original scoring has been divided by 10. The ranking and scoring of the changes has been cross-culturally validated (Masuda and Holmes, 1967; Komaroff and Holmes, 1968). Addition of the scores for each of the 43 items experienced within a given time period, usually six months, yields an overall score of recent life change, the LCU total. Excessive LCU totals have been correlated with illness behavior and the

tendency to develop illness (Rahe, 1972; Rahe and Flistád, 1974). Though tests in large populations have been highly statistically significant, the actual magnitude of the effects on the frequency of illnesses developed is quite small (Rabkin and Struening, 1976). The quantitative applicability of the scale to small numbers of individuals is questionable. Nevertheless, the scale is used here for two purposes. First, the scale items provide a general overview of other stresses the subject has faced in the recent past, and thus help to characterize the psychosocial milieu within which the terminal illness is occurring. Second, the LCU total can easily be calculated for use as an independent quantitative measure of recent or concurrent stresses.

To suit the population under study, the scale has been shortened from the original list. Several items which are inappropriate to the spouses of the terminally ill, or which apply to all have been deleted. The wording of some items has been simplified. The scoring for each item appears to its left in the questionnaire in Appendix II. To calculate the LCU total, it is necessary to add the following to the scores of the items check, if they apply to the subject (within the past six months):

44 units: Change in health of family member.

12 units: Christmas.

38 units: Financial situation much worse or better  
(Question #22, first or last response).

### 3. Psychological Assessment Scales.

#### a. Depression Scale (Page 8).

Assessment of depression in this study is accomplished with the Center for Epidemiologic Studies Depression Scale (CES-D) (Weissman and

associates, 1977). This is a very sensitive scale of 20 items derived largely from previously tested scales. It has been validated in five psychiatric populations and, most importantly for this study, 3845 randomly selected adults drawn from Kansas City, Missouri, and Washington County, Maryland.

The 20 items reflect mood or symptoms of depression. The subject is asked how often each one was experienced during the past week. There are four possible responses ranging from "Rarely or none of the time" to "Most or all of the time." For all but four items, these responses are scored from 0 to 3. The other four items, which express more positive feelings (Items #4, 8, 12 and 16) are scored in reverse, from 3 to 0.

The sum scoring of the items gives a score of depression. Scores tend to be higher in the nonpsychiatric population for women (mean score of 9.93) than for men (mean score of 9.10). A score of 16 or more has been defined and validated as a reliable indicator of depression. In the nonpsychiatric population, a score of 16 is 1.06 SD above the mean for men, 0.67 SD above the mean for women, and 0.80 SD above the mean for both sexes.

b. Anxiety, Hostility, and Somatization (Page 9).

The 30 items used on this page are derived from the Symptom Checklist 90 (SCL-90), a 90 item self-report checklist of symptoms (Derogatis and associates, 1973). The scale was developed to assess effects of pharmacotherapy in psychiatric outpatients and has been tested in various selected populations. Nine subscales of symptomatology are measured: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression,

Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism. Of these, Somatization, Anxiety, and Hostility are used. In addition, two individual items from the Depression scale concerning suicidal ideation and guilt are also used and regarded as individual symptoms.

The subject is asked to rate how much he/she was bothered by each symptom during the past week. One of five possible responses ranging from "not at all" to "extremely" is chosen. After these are scored from 0 to 4 units, the mean scores of all items in each of the three scales are calculated.

#### 4. Health Survey (pp. 10-12).

The health questionnaire used here is designed to elicit a comprehensive health history from the subject. It is derived from standard guides to medical histories (Klatskin, 1964; Prior and Silberstein, 1973). The goals of this section are to characterize symptomatology and illness associated with the period of time in which the spouse has been seriously ill. Preexisting illness is also elicited.

##### a. Current Major Illnesses

This is a list of 15 common serious adult medical conditions. The subject is asked to indicate if he/she has the illness now. If so, he/she is asked whether the illness started before or after the spouse became seriously ill.

##### b. Past Illnesses

The subject is asked to write in any serious past illnesses that are no longer active. He/she also lists the date each illness last gave trouble.

c. Operations.

The subject is asked to list the names and dates of operations not already indicated in the previous two sections.

d. Prescribed Medication.

This question asks for the names of medications currently prescribed to the subject. In case the subject does not know the names of the medicines, the investigator has a Physician's Desk Reference to identify pills.

e. Medication Intake During Spouse's Illness.

The subject is presented with the following classes of drugs: laxatives, antacids, pain medication, sedatives, tranquilizers, and sleeping pills. In each case he/she is asked to check whether the medication is currently used and whether he/she started to use it or increased the amount taken since the spouse became ill. The subject can list other nonprescription medication as well.

f. Habits.

This asks about the use of alcoholic beverages, cigarettes, coffee or tea, or other habitual substances. The subject indicates whether he/she has started to make use of each or increased the intake of each since the spouse became ill.

g. Medical Symptom Checklist.

This is a list of 90 somatic symptoms from all organ systems and regions of the body, derived from a standard medical review of systems. The subject is asked to check all symptoms which he/she has started to notice or which have definitely worsened since the spouse became seriously ill. Symptoms checked off are organized into the following groupings: General, Dermatological, Head-Eyes-Ears-Nose-Throat-Neck,



Breast, Cardiorespiratory, Gastrointestinal, Urinary, Locomotor, Neuro-muscular, Neuropsychiatric, Genitalia, and Extremities.

5. Data Sheet About Spouse (Page 13).

These ten questions provide information about the spouse and the spouse's terminal illness.

a. Demographic Data

Age (Question #1).

Occupation, Education, and Social Class (Questions #2, #3).

These are identical to questions #4 and #5 on page 1 of the questionnaire.

Employment Status (Question #4).

b. Data About Spouse's Illness.

Severity of Illness (Question #5). The subject is asked what the illness is that the spouse is suffering from. The purposes of this are to identify the disease process and to ascertain the subject's knowledge of the severity of the disease. The response is categorized as mild, serious, or terminal. Because of concern that some subjects might not know the severity of the disease, it was felt that this question could not be asked directly. For the subjects investigated in this particular study, all of whose spouses had cancer, identification of the disease process as cancer, malignancy, or tumor identified the illness as serious. Evidence that the subject knew that the disease process was not controlled, or that the disease was spreading or metastatic defined the disease as terminal.

Progression of Illness (Questions #6,#7). The subject is asked to identify where in the body the illness started and where it currently is.

Length of Illness (Question #8). The subject is asked how many years and months the spouse has been sick.

Length of Known Seriousness of Illness (Question #9).

This question asks how long the subject has known that the illness is serious. What constitutes serious may vary among subjects.

Symptoms of Illness (Question #10). The subject is asked to list symptoms currently most bothersome to the spouse.

### III.B, Population Selected for Study.

To study the effects of terminal illness on the family members, it was felt that subjects should have strong emotional ties to the patient and be in close proximity to him/her. Hospice of New Haven, Connecticut offers a clearly defined group of such people.

Hospice is a home care program for terminally ill patients and their families in the New Haven vicinity. Its interdisciplinary philosophy and practice of medicine are based on well established principles developed at British inpatient facilities for care of the dying, notably St. Christopher's Hospice of London. An attempt is made to tailor each element of care offered to the particular needs of the patient and family. Palliative symptom control and spiritual support are two essential aspects of care (Craven and Wald, 1975).

The patient population has been composed entirely of persons with cancer. All patients accepted into the program have poor prognoses and estimated life spans of generally no more than three months. Although the average length of life after entering the program is about three months, the actual length of life after admittance has varied considerably, from several days or less to several years. A few patients have experienced long-lasting partial remissions. For these persons, the trajectory of illness has leveled off to slow deterioration or stable chronic illness. Nevertheless, all patients carry a diagnosis of "terminal" cancer, and the disease process, though possibly slowed or stopped, is an ever present reality.

A requirement for acceptance into the Hospice program is the presence of someone to manage care in the home. This person, designated as the primary care person (PCP), takes major responsibility for being

with the patient and seeing that his/her basic needs are met. It was felt that the PCP's as a population fit the requirements to be subjects for this study. To restrict the population characteristics, it was decided to request participation only from spouses who were PCP's.

In the original plans for the study in Spring of 1977, it was hoped that 15 subjects could be administered the questionnaire over a two months period of time. At that time the Hospice census was 33 patients with about two thirds turnover in two months. Approximately two thirds of PCP's up until that time had been spouses. It was estimated that the participation rate would be about 50% to 70%. Using 50% as the participation rate, the projected number of subjects was calculated as follows:

$$N(\text{Projected}) = 50\% \times 61\% \times 33 \times 5/3 = 17 \text{ subjects}$$

By the time the project was started, some six months later, however, the census had decreased, and the number of spouses who were PCP's was much smaller than previously expected. The study was then expanded to include spouses who were not PCP's, but who lived in the same household as the patient. The ultimate defining variables of subjects, then, were that they be spouses who lived in the same house as the terminally ill patient. It was felt that this group would be almost as likely as PCP's alone to be affected by the presence of the terminal illness, and would constitute a suitable sample for testing of the questionnaire.

From January 3, 1978 to February 7, 1978, all potential subjects who had been involved with the Hospice program for one week or more were sent letters inviting participation in the study. A self-addressed,

stamped return postcard was enclosed. Copies of the letters and postcards appear in Appendix I. The names of those wishing to participate were given to the investigator, who contacted each and arranged a time and place to administer the questionnaire. Potential subjects who had not responded by February 21, 1978 were telephoned, and if the subject consented to participation at that time, he/she was contacted by the investigator in the same way.

To insure confidentiality, a secretary within Hospice handled all contact with potential subjects until they indicated affirmatively that they were interested in participation.

### III.C. Method of Administration

After arriving at the place agreed upon (usually the subject's house) and a minimum of preliminary introductions, the investigator moved to a comfortable place where the subject would be able to sit down and write (usually the kitchen table). He then thanked the subject again for being interested in participating, explained the nature of the consent form, and presented it to the subject to read and sign. The subject could ask any questions at any time. The consent form conformed to the specifications of the Human Investigation Committee at Yale. (Both the HIC proposal and the consent form appear in Appendix I.)

After the subject had read and signed the consent form, the investigator then administered the questionnaire, explaining that should he/she have trouble with any questions or sections, he/she should feel free to ask for clarification. For questions requiring clarification, the investigator was particularly careful not to bias the subject's answers. In certain circumstances, it was necessary for the investigator to read certain sections (and in one case the entire questionnaire) and to mark the answers in particular sections in order to facilitate

completion of the questionnaire. In such cases, the investigator was careful to mark only when the subject's answer matched one of the options offered. Ambiguous responses were reflected back to the subject without partiality until one of the available choices was selected.

After completion of the questionnaire, the subject invariably wished to discuss some aspects of their spouse's care or their own particular difficulties. The investigator listened attentively and responded sympathetically. If a subject's needs were particularly pressing, the investigator suggested and encouraged contacting the Hospice staff. In one case a woman claimed to have particular problems communicating her needs to the Hospice staff and wished the investigator to do that for her. This was done promptly.

As soon as possible after the session, the investigator coded the questionnaires (see Appendix IV) and entered the results into a data book. The investigator also entered in uncoded prose form his overall impressions of general problem areas, sources of stress, social dynamics, and other information not apparent from the coding.

The overall flow of subjects through the study appears in flow chart form in Appendix III.

#### IV. Testing of the Questionnaire

##### A. Sample Tested.

During the time period of the study a total of 20 persons were sent a letter inviting participation. 4 of these accepted the invitation and were subsequently contacted. 11 persons actively refused participation by returning the enclosed postcard or by telephone followup. 5 subjects did not return the postcard and were not recontacted; 4 because of the death of the spouse within several days after the letter was sent, and 1 because of continuing severe emotional crisis. The overall acceptance rate based on the total of 20 was 20%. Excluding the 4 subjects whose spouses died soon after the letters were sent, the acceptance rate was 25%.

One of the subjects (#C) was bereaved after agreeing to participate. At his request and with the permission of Hospice, he was recontacted several weeks later and administered the questionnaire. He was asked to respond to the questions as they applied to his status at the time the questionnaire was administered and then to respond again as they applied to the last one or two weeks of his wife's illness.

A fifth subject (#D) was interviewed. This was a 24 year old woman who was the PCP for her mother. She returned the postcard herself, indicating that it would be impossible for her elderly father to participate, but that she was interested. With permission from Hospice she was contacted and filled out the questionnaire.

Information about reasons for nonparticipation is known for several subjects. In three cases, including the one above, the children refused participation for the subjects. In one case there was evidence of strain ("too difficult at this time") and in another, a sense of

hopelessness ("Nobody can help me"). One subject would "do anything for Hospice, except be interviewed."

Data comparing the 4 spouse-participants with 16 nonparticipant appears in Table IV. There is little difference between the samples in sex, mean age, race, and role as PCB. None of the participants were Italian, suggesting a possible ethnic bias of Italians--at least older Italians--not wanting to participate. A major difference concerns the length of contact with Hospice; though the ranges are similar, the mean is much higher for the participants. Only one participant had been associated with Hospice for one month or less, while 7/11 of the active refusers had such short associations. Short length of contact with Hospice was probably related to an unstable medical condition (unstable enough so that Hospice would be considered as a possible choice of treatment). This may have created a crisis situation, which would make participation in the study difficult or impossible.

An important source of bias for this testing is indicated by the fact that all of the subjects assessed their health as good or excellent. Figures are not available for nonparticipants but one can compare Buckingham's (1977) preliminary figures of 36% fair-poor health. It is possible that subjects with worsening health may have tended not to participate.

It must be noted that for all of the above relationships, the number of participants was not great enough to draw any statistically significant inferences. Those await a future study.

#### IV.B. Characteristics of Participants.

Selected data from participants appears in Tables V, VI, and VII.



Table IV

Sample Bias

Variables	Sample Tested	Sample Not Tested		
	Parti- cipants	Total Non-tested	Active Refusers	Nonres- pondents
N	4	16	11	5
Sex	2M, 2F	9M, 7F	9M, 2F	0M, 5F
Age				
Mean	68.5	67.5	67.5	67.5
Range	66-71	49-85	49-85	52-78
Racial Group	3W, 1B	15W, 1 unknown	10W, 1 unknown	5W
Length of Contact with Hospice				
Mean (mo.)	12	3	4	0.25
Range (mo.)	1-29	0.25-35 at least 7/16	0.25-35 at least 7/11	0.25-0.5
Ethnicity	0/4 Italian	7/16 Italian	7/11 Italian	unknown
Subjects as PCP	4/4	14/16	9/11	5/5
Subsequent Death of spouse (Within Two Weeks of Letter Being Sent)	1/4	8/16	4/11	4/5

Table V  
Selected Data from Participants

Variables	<u>Subjects</u>				
	A	B	C	D	E
Relationship to Patient	Spouse	Spouse	Spouse	Daughter	Spouse
Sex	F	F	M	F	M
Age	71	70	67	24	66
Race	W	W	W	W	B
Ethnicity	Russian/ Polish	Irish	German/ Scand.	Italian	Afro- American
Length of Serious Illness (months)	5	168	39	30	48
Length of Relationship with Hospice (months)	1	16	2	3	29
Social Class	III	V	V	V	II
Projected Change of SES score	0	0	0	0	0
Employment	retired	retired	retired	full-time	retired
Change in Financial Situation During Illness	same	much worse	little worse	much worse	little worse
Medical Insurance for Private MD office visits	yes	yes	no	yes	yes
LCU total	220	128	137	299	174
Perceived General Health	excellent	good	excellent	good	excellent

Table VI  
Outcome Data from Participants

Variables	<u>Subjects</u>				
	A	B	C	D	E
Depression score	4	2	38	30	11
Anxiety score	0	0	2.00	1.80	0
Anger/Hostility score	0	0	1.50	1.00	0
Somatization score	0.25	0.17	1.17	0.83	0.67
Current Major Illness:					
Started Before Patient's Illness	Arth- ritis Diabetes	Arth- ritis		Asthma	Arth- ritis
Started After Patient's Illness	None	Diabetes HBP Stomach/ bowel	Phle- bitis		Diabetes HBP
Increased Use of Medicines and Habits:					
Antacids	no	yes	yes	no	no
Aspirin/pain	no	yes	no	yes	no
Sedatives or Tranquilizers	no	no	no	no	no
Cigarettes	no	no	no	yes	no
Alcohol	no	no	no	no	no
Number of symptoms checked	0	6	7	20	1
Similarity of Subject's and Patient's Symptoms	no	same body region as site of origin of cancer	no	same body region as most troublesome symptom	no

Table VIIHelp-seeking Data from Participants

<u>Variables</u>	<u>A</u>	<u>B</u>	<u>C</u>	<u>D</u>	<u>E</u>
<b>Professional Support:</b>					
Personal Md	never	several times	rarely	never	several times
Other MD	never	several times	rarely	rarely	never
Psych.	never	never	never	never	never
Nurse/MSW/ Other Health	never	never	monthly	more than monthly	never
Minister	never	never	more than monthly	never	never
Hospice Staff	several times	more than monthly	several times	monthly	several times
<b>Nonprofessional Support:</b>					
Overall Access: Score	18	19	18	17	15
Overall Utili- zation score	26	26	22	16	21
<b>Overall Outcomes</b>					
Serious Medical Illness, No Medical Treatment	no	no	no	no	no
Evidence of Psych. Disturb., No Psych. Treatment	no	no	yes	yes	no
Evidence of Psych. Disturb. Medical Treatment	no	no	yes	yes	no

The 5 subjects interviewed varied somewhat in demography and other basic information. Nearly all (4/5) the subjects had the following characteristics: age between 65 and 71, white racial group, retirement, illness length more than two years, worsening of financial situation during the illness, and medical insurance coverage for private physician's visits. There was no indication of a change in SES that would result from the impending death. As noted above, all had good health or better. All but one had relatively few recent life changes, and the LCU totals for these are well below 300. Subjects included persons of both sexes, three different social classes, and both short and long association with Hospice. Thus, although the sample is small, it is not uniform.

Outcomes measured are quite variable. 2 subjects showed marked evidence of psychiatric disturbance from depression and anxiety scores. It should be noted that the scores of one subject (#C) were derived from answers given about three weeks after his spouse's death. At that time, he may have been more sensitized to feelings and symptoms, and his retrospective responses would have been different from the others because of it. His psychiatric indices after the illness were all considerably lower than before the illness, but the depression score was still very high (score of 26). Comparing feelings between two highly charged periods of time before and after his wife's death, may have added considerable distortion to his data. In any case, it is hard to compare his data with that from the others. He gave no indication of clinical depression while the questionnaire was being administered.

Past and present illness were quite variable. Two of the subjects had developed diabetes and hypertension during the course of the illness, but in both cases, the length of the illness (the length it was considered

serious) was very long; by the time of the interview they had been present for years. It would be difficult to separate out the effects of aging from the effects of serious or terminal illness. The baseline health of all the subjects before the spouse's illness was fairly good. Of the three persons with arthritis, none had the crippling or rheumatoid variety. The asthma in subject #D had been mild. None of the pre-existing illnesses worsened during the spouse's illness.

Three subjects increased medication use during the illness, and one subject increased her use of cigarettes. The reasons for the increased use of pain medicines in subject #D had to do with multiple dental procedures and HEENT symptomatology, which accounted for seven of the twenty symptoms she checked. The numbers of symptoms checked by other subjects were much lower. In no instance was there evidence of untreated serious medical illness by the symptoms checked.

There were no cases in which the patient and subject shared the same troublesome symptoms. In two cases (#B and #D) there was a match of bodily regions. In one case the patient had prostatic cancer and the subject had nocturia. In the other, the patient had muscle paralysis, while the subject had tremors and shakiness. This subject (#D) also had several neuropsychiatric symptoms which may be related, but which were grouped under another category. Both matches were probably coincidental and do not reflect identification phenomena.

Subjects had evidence of strong social and professional supports. Subjects #B, #C, and #D all had one or more types of professionals with whom they had frequent contact and whom they found supportive. Subjects #A and #E had infrequent contact with any professionals. Most subjects, including #A and #E, had high access to and utilization of nonprofessional

support. Subject #E received considerable support from members of his church who came to visit his wife almost daily. Something not elicited by the questionnaire was the importance of a family pet to social support; Subject #B had a pet dog that was remarkably affectionate and supportive to the entire family. In general, all subjects had to restrict outside social activities severely, but most had frequent visits to their homes from friends and relatives. The one exception was #D, who seemed quite socially isolated, as reflected by her low utilization of social support score and by comments she made about her job and home life.

Finally, overall outcomes reveal that subjects #C and #D did not receive psychiatric help, despite the evidence of psychiatric disturbance, but on the other hand were receiving medical help. For #D this help actually came from a dentist, whom she saw frequently for mouth problems. Though not asked, it is possible that the other category of health professionals she checked may have included a social worker or nurse from whom she received counseling for psychiatric problems. Subject #C had developed a phlebitis, and though it had cleared, he sought definitive therapy. His concerns for this problem and for his health in general seemed to help him work through some of the grief he had experienced both before and after his wife's death. Neither of these subjects gave any indication, however, of actively seeking medical care specifically for emotional or psychiatric problems.

## V. Conclusions

### A. Critique of Questionnaire.

In this small sample, the questionnaire proved easy to administer and caused absolutely no disturbance or strain in subjects. Even in subject #E, for whom the entire questionnaire with choices had to be read aloud, there were no problems. The mean time taken to fill out this questionnaire was 55 minutes. Subject #E took the longest, with 75 minutes, and subject #B took 70 minutes. Subject #B was interrupted several times by other family members, which accounted for 15-20 minutes. The other three subjects took 40-45 minutes, the upper limits of the expected amount of time.

Whether or not the questionnaire assessed what it was supposed to is difficult to analyze, given the small number of subjects and lack of objective validation methods. The only other information with which the questionnaire data could be compared comes from the open discussions after the questions had been filled out. On this basis, several problems became apparent concerning social support and strain, two areas that the questionnaire is designed to characterize.

From the discussion, subjects #A and #D seemed to be under strain and to have significant difficulties coping with the terminal illness. By the questionnaire responses, subject #A showed no evidence of either cause or effect of such strain. She claimed she was having particular difficulties communicating with her sick husband and with the Hospice staff, and seemed quite distressed about it. The fact she had this problem is not elicited at all in the questionnaire. At the same time, her health and psychological surveys are almost completely negative



for illness or symptoms.

On the other hand, subject #D showed considerable evidence of strain from psychiatric indices and medical symptomatology. A possible source for this, also elicited by the questionnaire, was social isolation (low utilization of nonprofessional support, Table VII). An equally important factor contributing to her strain, not sought in the questions, though, was the considerable effort she spent coordinating her mother's care. From the responses of both #A and #D, it would appear that questions about the difficulties caring for the terminally ill relative should be included.

The derived variables (Appendix IV) of overall access to and utilization of nonprofessional support are useful indices of social support. They correctly identified subject #D as someone with decreased utilization of social resources, when compared with the other subjects. Subject #B had no particular problems with either of these variables, but one aspect that was important to her case and not asked about was the presence of a pet. Her remarkable pet dog, which was treated much like a member of the family, was obviously an ongoing source of support for her and her husband. It may be useful to query this fact of home life, as for some it may be an integral part of the social support system.

Psychiatric morbidity is assessed fairly objectively and efficiently by the psychiatric scales. Of the two subjects who had evidence of psychiatric disturbance by the scales, #D showed evidence of such distress during the discussion, while #C did not. The fact that #C had been recently bereaved probably skewed the results considerably. As Lindemann (1944) noted, acute grief can come in waves of sadness and depressed mood. When seen, #C was probably experiencing a lull in such emotional activity, and he consequently appeared quite emotionally solid and intact while being

administered the questionnaire. The grief processes may have influenced how he evaluated and remembered his thoughts and feelings before death. With such processes so recent, he may have been sensitized to his inner feelings and remembered them more vividly, thus tending to increase his scores. The opposite effect may have occurred with subject #A, whose psychiatric indices and medical symptoms were unusually low. Part of the reason for this may have been the relatively short serious illness of her husband, when compared with that of the others. Could it also be that under the stress she was facing, she may have had diminished perception of symptoms?

It is impossible to assess either of these without further data. In any case, comparing data from bereaved and nonbereaved subjects needs to be done with caution.

The overall outcome situations (Appendix IV) may be useful ways of summarizing the data, but the exact criteria for what constitutes serious illness and lack of help-seeking behavior are not well developed. Some of the help-seeking behavior noted may have had little to do with the existing illness processes. Help-seeking needs to be related more directly to symptoms and disease. Ideally, obtaining accurate, well-documented medical records would provide such data, at least data to validate this section of the questionnaire.

Similarly, criteria for medical illness are not objective. As a fourth year medical student, I may be able to assess grossly serious medical illness by history, but there are bound to be subtle gradations in symptomatology that would make me rely on "clinical judgment" to determine whether someone has illness serious enough to require medical attention. Clinical judgment suffers from subjective variability over

time and between persons, especially for subtler disease processes.

The 57-item medical checklist of Maddison and Viola (1968) might be adapted for use here; though not as detailed as this questionnaire, it offers a cross-section of psychiatric and medical symptoms of varying severity and a weighting system based on that severity. Of course, the system of weighting based on seeking medical attention or hospitalization could not be used here, as it is vital to this study to separate out morbidity from help-seeking. In any case, at least minor modifications need to be made to the health survey, and objective criteria need to be developed to assess disease in this population.

Three other problems that suggest places for revision of the questionnaire concern identification phenomena (matching of patients' and subjects' symptoms), length of illness, and the definition of the illness as serious.

The matching of subjects' and patients' symptoms to check for identification phenomena may be useful, but it is unproven by this sample, as there were no definitive matches. The matching of bodily regions as defined here is probably useless, and prone to false-positive error. Both of the matches by bodily region here were probably coincidental. If the symptoms were reorganized according to narrower groupings of more interrelated symptoms, it's possible this would be more reliable.

The questionnaire treats all subjects equally, but it may offer misleading information about subjects when the patient's illnesses are extremely long or fluctuating in trajectory. For example, subject #B's husband's illness was considered serious 14 years ago. Her health survey and help seeking questions cover that period of time. It is impossible

to distinguish between disease related to the husband's illness and disease related to the natural process of aging. Furthermore, important information was missed. She stated that twice her husband had been near death; during those times she developed worsening symptoms, all of which resolved when his condition stabilized, and few of which she now remembers.

It is possible that some persons like #B may develop symptoms only as the patient worsens. If the questionnaire is administered after the crisis has past, some of these symptoms may no longer be present and are likely to be missed or forgotten. If the illness is extremely long, then it is important to define when it became significantly worse, and if possible focus some of the questions on that time period in addition to the illness as a whole.

One source of confusion in the study concerns the length the illness is considered serious. The ultimate variable desired here was the time span since the illness was first determined to be "terminal." There was concern, however, that asking this directly would disturb some subjects. It is inevitable that some subjects would tend to defend against the fact of impending death by denial or another psychological mechanism. To ask how long the patient has been terminally ill, would tend to break down such defenses and could cause the subject to become upset. Instead, then, the questionnaire asks how long the illness has been serious. Exactly what constitutes serious is not well characterized and needs to be specified more exactly. The time period also needs to be specified closer to the beginning of the questionnaire than the last page where it is now asked. Certainly, it should be asked before other questions that use it as a time reference.

Despite these difficulties, the questionnaire provided considerable

information about the sample studied, with a minimum of invasiveness. It proved to be easy to administer, code, and analyze. In future studies in this population, whether at Hospice or elsewhere, it can serve as a basis from which to develop better, more objective instruments of analysis.

#### V.B. Critique of Study

The last questions to be asked concern the study as a whole. Was Hospice the best place to do it? Was it done in the best way possible?

In several ways Hospice was a very good place. The population of subjects is well defined. The fact that Hospice is a home care program means that the investigator would be able to obtain data about terminal illness relatively unbiased by the stresses and strains of hospitalization. Staff members have generally close, positive rapport with patients and subjects (by my sample). For the investigator to be able to enter into the private life of the dynamic, sometimes crisis oriented situations of the family of the terminally ill, it is important for him to be sponsored by an organization that the prospective subjects trust. Hospice offers this.

However, there were difficulties. Most of these centered around the fact that Hospice is currently in transition: from being a home care program to having an inpatient facility, and from being nationally funded to being self-supporting. In order to accommodate my project, Hospice needed to formulate a policy on research in general. This took time and energy, and forced the starting time of the project further and further back. Despite these difficulties, though, the final system of inviting participation by letter and obtaining information about subjects through Mrs. McCarthy, who acted as a liaison, proved quite workable.

Another "difficulty" with Hospice that affected the goals of this project, is that the subjects are well intervened. Several subjects commented on the continuity of care, the open communication at critical times, and the general supportiveness of the Hospice staff during the terminal illness; all were particularly appreciated and all cut down enormously on the confusion and strain that could be expected to contribute to worsening health. The study was designed based upon observations in an intensive care unit; if the results demonstrate anything, they show how different is the atmosphere between the home served by Hospice and an ICU. Because of the attention they receive, though, Hospice PCP's would be unlikely to have medical or psychiatric illness for which they are not receiving help. The intervention that Hospice provides can itself serve as that help, as exemplified by two subjects who discussed their own personal or health needs with Hospice staff. Thus, Hospice may not be the best place to attempt to study the ultimate target population of this investigation, namely, those family members with health problems not receiving help.

A potentially serious problem with this study is the low rate of participation. Most studies of the bereaved have higher rates of 40%-70% (Clayton, 1974; Crisp and Priest, 1972; Maddison and Viola, 1968; Ball, 1977). Most of these involved one interview and/or a self-report questionnaire. The most extensive study by Parkes and Brown (1972), involving five interviews, had a comparable rate of 22%. Parkes and Brown offered information about refusers; 14 of these were contacted by telephone two years into the study, and basic data was obtained. There were no significant differences noted between them and the participants. If that is true for the current sample, all well and good. However, the

differences in ethnicity and length of contact with Hospice suggest possible bias in the data obtainable through the methodology of this study.

As implied by the differences between participants and nonparticipants in this study, persons in crisis may be difficult to investigate. Subjects approached after only one week may have been unprepared for the investigation. Extending the delay of sending the letter of invitation from one week to two (after admittance into the Hospice program) may increase participation, but many who would accept the invitation might be out of the crisis by then. In order to gain further access, it would probably be necessary to adopt a more interventionist role in the subject's and/or patient's therapy.

This was not done in this study for several reasons. First, the investigator was not qualified; he had no professional certification and had not had any of the specialized training Hospice requires of volunteers and new staff. Second, it was felt that such a role would impair objectivity in the research findings. In addition to these there may have also been unvoiced concerns that such a situation could become coercive, that the subject might believe that refusal would jeopardize his/her fair treatment, despite whatever disclaimers might appear on a consent form.

All of these are valid reasons. The organization of the current study, its safeguards and attempt at objectivity, probably work in the best interests of Hospice and the patients and families it serves. In so doing, though, it may not be possible to gain access to the group of persons--those in crisis as I observed in the Intensive Care Unit--who

are likely to have severe untreated medical or psychiatric problems. If one is willing to trade off some of the objectivity, it may be possible to gain closer access to the situational crisis affecting the family members to make quantitative observations about those who would tend to have more troubles. This could be done through an investigator playing a more active role in intervention, or conversely, to have those in an interventionist role systematize their observations and evaluative techniques in a quantifiable manner. Clear establishment of priorities-- would be of utmost importance.

This has been done in the terminally ill by hospital chaplains (Carey, 1975). There is no reason why, if done sensitively and with the subject's care as highest priority, quantitative research cannot be done with the family members of the terminally ill who are in crisis. Research with both families in and families out of crisis would provide a more complete picture of their situation. Such quantitative information would serve to characterize more fully some of the processes noted by Maddison and Raphael (1972) and others who have made extensive empirical observations of this population.



## APPENDIX I

HUMAN INVESTIGATION COMMITTEE PROTOCOL  
LETTER, POST CARD, AND CONSENT FORM

PROTOCOL FOR RESEARCH INVOLVING HUMAN SUBJECTS

YALE UNIVERSITY SCHOOL OF MEDICINE  
YALE-NEW HAVEN HOSPITAL

Title of Project:

Morbidity and Help-seeking Behavior in  
the Spouses of the Terminally Ill

Date July 1, 1977

Resubmitted November 4, 1977  
Resubmitted December 21, 1977

Principal Investigator:

Arthur M. Gershkoff, Yale University School of Medicine, class of 1978

Other Investigator(s):

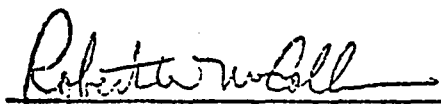
Investigator Responsible for Correspondence: Dr Adrian Ostfeld

Telephone extension: 62732

Mailing address: 404 LEPH, Yale

School and Hospital Department(s)

Approved for Submission to HIC:



Signature of Chairman, Department of EPID

Rev. David C. Duncombe  
HIC Primary Reviewer

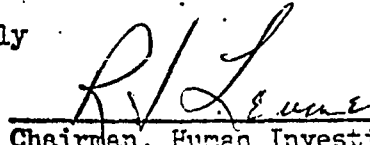
Signature of Chairman, Department of

Signature of Chairman, Department of

Attention: The completed protocol consists of four parts: I. Face Sheet; II. Description of study; III. Human subjects; and IV. Consent form. This outline contains parts I, II, and IV. Part III is material required by the U. S. Department of Health, Education, and Welfare, and may be a copy of the page(s) included in your grant proposal. (See guidelines p. 6) Study the 1976 revision of Human Investigation Committee guidelines as you prepare the protocol. Note time-table on page 3.

For HIC Use Only

11/17/77  
Date Approved

  
Chairman, Human Investigation Committee

1/11/78 Amendment  
Dates Reapproved

Amendment - interim approval 12/22/77

## II. DESCRIPTION OF STUDY

### A. Purpose

This is a pilot study to characterize medical and psychological symptomatology and patterns of help-seeking behavior among the spouses of terminally ill patients. The study will form part of the investigator's thesis requirements for the Doctor of Medicine degree at Yale. It is hoped that the information gained from this study will assist in the future design and execution of more controlled studies in the field.

### B. Background (for references, see appendix)

During the past fifteen years, many authors have written about bereavement and its effects upon health. Parkes (1,2), Clayton (3,4,5), Maddison (6), and others have investigated conjugal bereavement and the medical and psychological morbidity associated with it. Those and others (7) have discussed the phenomenon of anticipatory grief and its similarities to the process of grief. Some authors (5,7) believe that many, if not most people faced with prolonged terminal illness in a loved one will manifest anticipatory grief.

In routine questions asked by Hospice staff to patients and their families in the Hospice Home Care Program, 36% of primary care persons reported fair or poor health (8). "Primary Care Person" (PCP) refers to the individual most responsible for the day-to-day care of the terminally ill patient in the home. Preliminary data from an evaluation of the Hospice Home Care Program (9) show that anxiety is high in PCP's, frequently higher than in the terminally ill patients themselves. Clayton, et. al. (5) reported 23% of her subjects with terminally ill spouses to have a depressive symptom complex before bereavement.

From this, the first hypothesis of this study is that psychological and medical morbidity in the spouses of the terminally ill exists and can be further characterized. To this investigator's knowledge, medical morbidity perse has not been well characterized in this population.

Parkes (10) noted a significant increase in physician consultation rates for London widows in the periods after bereavement, above pre-bereavement rates. One explanation put forth (Clayton (3)) is that subjects tended to postpone consultation while their spouses were alive. It is frequently observed that when faced with terminal illness, many family members tend to concern themselves with the dying loved one (culminating in a vigil) and neglect their own health and bodily needs.

The second hypothesis of this study is, then, that some of the subjects will not be receiving medical care for what are significant health impairments.

### C. Specific location of study.

The investigator will meet with subjects in their homes or in the Hospice office, as they desire.

#### D. Probable duration of project

Subjects will be contacted and seen over a 4-6 week period beginning approximately December 27, 1977.

#### E. Experimental Method: An orderly scientific description of the intended procedures as they directly affect the subject.

15 persons whose spouses are Hospice patients will be given a self-report questionnaire to fill out. The questionnaire will consist of the following sections:

1. Data Sheets: These contain demographic data and information about the subject's cultural and ethnic background, family and friends, accessibility to his/her physician, financial status, general health, and help-seeking behavior.
2. Recent Life Events Scale.
3. Psychological Assessment Scales.
4. Health Questionnaire: Contains information about present and past illnesses, medications taken, habits, and a checklist of medical symptoms.
5. Data Sheet Regarding Spouse: This contains information about the terminally ill spouse, in particular, about the nature and duration of his/her illness.

The Recent Life Events Scale is adapted from Rahe (11). The Psychological Assessment Scales will incorporate the Center for Epidemiologic Studies Depression Scale (12) and the anxiety, anger-hostility, and somatization subscales of the Symptom Checklist-90 (13).

The questionnaire will take approximately 30-45 minutes for the subject to complete. The investigator will be present during that time to help clarify the questionnaire and facilitate completion of as many items as possible. When the questionnaire is finished, the investigator will ask the subject if he/she has any questions. He will remain available to discuss these questions or any aspect of the questionnaire desired by the subject.

#### F. Material inducements that will be offered to subjects: e.g. direct payment, free hospitalization, medication, food, etc.

None.

#### G. Clinical Research Center Protocols only

Does not apply.

### III. HUMAN SUBJECTS

#### A. Subject Population

15 persons whose spouses are terminally ill cancer patients currently receiving care from Hospice Home Care. Subjects will have been associated with Hospice at least 3 weeks, and will be both male and female without age restriction. They will reside in the same house as their respective spouse and/or will have been designated as the PCP for their spouse.

#### B. Potential Risks

The tiring or upsetting of the subject.

#### C. Consent Procedures

Initial identification of subjects or potential subjects (those subjects whose terminally ill spouses have been associated with Hospice less than 3 weeks) will be made by Hospice staff. Subjects whose spouses have been associated with Hospice for at least one week are eligible for initial contact.

Initial contact will be made by letter to each subject (see appendix). The investigator will receive the names and telephone numbers of all subjects who apply affirmatively to the request by returning the enclosed self-addressed stamped postcard. He will then contact each subject and arrange a time and place to administer the questionnaire. Before the questionnaire is to be filled out, the subject will read and sign the consent form.

#### D. Protection of Subjects

The subject will be informed as part of the consent procedure that he/she is free to postpone or refuse to continue (or start) the questionnaire at any time. Should he/she tire or feel uncomfortable or upset, the investigator will offer to stop or postpone the questionnaire, and if necessary, will leave the subject or postpone the subject's participation in the study. If the subject requests the investigator to leave, he will do so.

Questionnaires will be coded, verified, and placed in sealed envelopes as soon as possible after completion. Subjects will be identified by a code number on the questionnaires, envelopes, and data cards. Names corresponding to the code numbers will be known only to the investigator. A list of names contacted by the investigator will be provided to Hospice. Information arising from a particular named subject's questionnaire will not be shared with anyone, including the Hospice staff or the subject's spouse, without the express permission of the subject. The list of names and corresponding code numbers will be kept locked in a place accessible only to the investigator.

### E. Potential Benefits

While the information from this study will probably not benefit the subjects or their terminally ill spouses, it is hoped that it will help sensitize physicians and other health workers to the psychological and medical needs of future persons who have terminally ill spouses.

By filling out the questionnaire, a subject may discover that he/she has a medical problem for which he/she has neglected or postponed treatment. This may serve as an impetus for the person to seek corrective therapy.

### F. Risk/Benefit Ratio

The potential benefits, particularly to future persons with terminally ill spouses, would seem to outweigh the risks to those subjects studied.

## REFERENCES

1. Parkes, CM, Bereavement: Studies of Grief in Adult Life . New York: International Universities Press, 1972.
2. Parkes, CM, Brown, RJ: Health after Bereavement: A Controlled Study of Young Boston Widows and Widowers. Psychosomatic Medicine, 34:449-461, 1972.
3. Clayton, PJ: The Clinical Morbidity of the First Year of Bereavement: A Review. Comprehensive Psychiatry. 14(2): 151-157, 1973.
4. Clayton, PJ: Mortality and Morbidity in the First Year of Widowhood. Archives of General Psychiatry, 30:747-750, 1974.
5. Clayton, PJ, Halikas, JA, Maurice, WL, Robins, E: Anticipatory Grief and Widowhood. British Journal of Psychiatry, 122:47-51, 1973.
6. Maddison, D, Viola, A: The Health in Widows in the First Year Following Bereavement. Journal of Psychosomatic Research, 12:297-306, 1968.
7. Schoenberg, B, Carr, AC, Kutscher, AH, Peretz, D, Goldberg, I, eds., Anticipatory Grief. New York: Columbia University Press, 1974.
8. Personal communication from Natalie Tyler, research data analyst at Hospice.
9. Personal communication from Robert Buckingham, Director of Research at Hospice. Data to be discussed in his thesis: Hospice Home Care Evaluation Dissertation for Dr. P.H., Yale University, in progress.
10. Parkes, CM, Bereavement: Studies of Grief in Adult Life, p. 200.
11. Rahe, RH; "Life Change and Subsequent Illness Reports," in Gunderson, EKE, Rahe, RH, Life Stress and Illness. Springfield, Ill.; Charles C. Thomas, 1974.
12. Weissman, MM, Sholomskas, D, Pottenger, M, Prusoff, B, Locke, BZ: Assessing Depressive Symptoms in Five Psychiatric Populations: a Validation Study. New Haven, Ct., 1977 (Unpublished paper).
13. Derogatis, LR, Lipman, RS, Covi, L: SCL-90: An Outpatient Psychiatric Scale: Preliminary Report. Psychopharmacological Bulletin, 9(1):13-27, 1973.

IV. CONSENT FOR PARTICIPATION IN A RESEARCH PROJECT  
YALE UNIVERSITY SCHOOL OF MEDICINE

Invitation to participate and description of project:

You are invited to take part in a study that will help provide information about the health and feelings of people with seriously ill family members. Through Hospice of New Haven, we have been told that your husband or wife is seriously ill. Physicians and other health professionals need more information about the health and feelings of people like yourself with seriously ill family members. Although you and your husband or wife will probably not benefit from the research project, it is hoped that the information in it will be of help to persons responsible for providing care to families faced with similar circumstances.

If you agree to participate, you will be asked to complete several data sheets about yourself, your husband or wife, and your family and friends, several questionnaires about your health and recent experiences, and two questionnaires that ask about your feelings. These will take about 30-45 minutes to fill out. Your data sheets and questionnaires will be coded and kept in the strictest confidence. No one except myself will see them or know your identity.

After you have finished the data sheets and questionnaires, I will check them in your presence to see that as many items as possible have been filled out. You are free to refuse to answer any particular questions that you find irritating or embarrassing. If you find any items confusing or difficult to answer, you may



ask me to clarify them for you at any time.

You are free to refuse to participate in the study, and you may postpone or refuse to continue the questionnaire at any time should you feel tired or uncomfortable. The care you and your husband or wife are receiving from Hospice will in no way be affected by your decision to accept or refuse participation in this study.

Before you sign this form, please ask any questions on any aspect of this study that is not clear to you. You may take as much time as necessary to think this over.

Authorization: I have read the above and agree to participate in the project described above. Its general purposes, potential benefits, and possible hazards and inconveniences have been explained to my satisfaction.

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Person obtaining consent

\_\_\_\_\_  
Date

At Hospice, we are interested in serving you and others like yourself in the best way possible. You and your family help us in that process. We learn very much from all of our patients and their families, and are always trying to improve our skills and knowledge. Still, there is a great need among health professionals to learn more about the health and feelings of patients and families whom they serve.

We would like to invite you to participate in a Yale University research study that explores the health and feelings of people like yourself with seriously ill family members. A senior medical student at Yale, Arthur Gershkoff, has organized this study with Dr. Adrian Ostfeld, Professor of Public Health at Yale. Both Mr. Gershkoff and Dr. Ostfeld have been interested in the health and feelings of seriously ill people and their families for a long while, and hope to use the information in this study to help other physicians and health workers who are also interested. Mr. Gershkoff would like to meet with you and has a questionnaire for you to fill out to aid his study. The questionnaire will take about 30 to 45 minutes to fill out, and Mr. Gershkoff will be there to help answer any questions or concerns you have about it.

We think this is an important study, and we hope that you will seriously consider participating in it. If you'd rather not participate, you are perfectly free to refuse, and the care you and your husband are receiving from Hospice won't in any way be affected. If you would like to participate and have Mr. Gershkoff contact you, please check the top square on the enclosed self-addressed stamped postcard and drop it in the mail.

Thank you for your consideration. We look forward to continuing to serve you and your family in the future.

Sincerely,

William S. Norton, M.D.  
Signing for  
Sylvia A. Lack, M.B., B.S.  
Medical Director

/kb  
enc.

hospice, inc  
hospice, inc

871

, 765 prospect street . new haven . connecticut 06511

home care (203) 787-5779

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Thank you for your consideration. We look forward to continuing to serve you and your family in the future.

Sincerely,

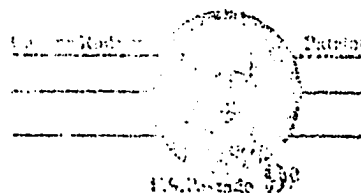
William S. Norton, M.D.  
Signing for  
Sylvia A. Lack, M.B., B.S.  
Medical Director

/kb  
enc.

## SELF-ADDRESSED STAMPED POSTCARD

YALE UNIVERSITY RESEARCH STUDY  
HOSPICE HOME CARE

- ☐ Yes, I am interested in participating in the study. Please have Mr. Gershkoff contact me to arrange a time.
- ☐ No, I would prefer not to participate in the study.



HOSPICE INCORPORATED  
765 Prospect Street  
New Haven, Connecticut 06511

APPENDIX II

QUESTIONNAIRE

PERSON ADMINISTERING QUESTIONNAIRE: Arthur M. Gershkoff

SUBJECT NUMBER: \_\_\_\_\_

### DATA SHEETS

DIRECTIONS: Please fill in the blanks, or place a check mark beside the answer that best describes your situation.

#### General Information

1. Your sex: ☐ Male ☐ Female
2. Your age in years: \_\_\_\_\_
3. Your racial group: ☐ White ☐ Black ☐ Hispanic ☐ Other
4. Your occupation: ☐ Higher executive, proprietor of large concern, or major professional  
☐ Business manager, proprietor of medium-sized business, lesser professional, or graduate student  
☐ Administrative personnel, or proprietor of small independent business  
☐ Clerical or sales worker, technician, owner of little business, or undergraduate student  
☐ Skilled manual employee  
☐ Machine operator or semi-skilled employee  
☐ Unskilled employee  
☐ Unemployed—no previous job skill  
☐ Housewife/house-husband
5. Your education: ☐ Graduate or professional training  
☐ Standard college or university graduate  
☐ Partial college or business college  
☐ High school graduate  
☐ Partial high school training  
☐ Completed 7-9 grades  
☐ Less than 7 years school
6. Employment status: ☐ never worked ☐ unemployed  
☐ retired ☐ part time  
☐ full time

#### Ethnic and Religious Background

7. Ethnic group: ☐ Italian ☐ German/Scand. ☐ Irish  
☐ Puerto Rican ☐ Russian/Polish ☐ Other  
☐ Afro-American ☐ Anglo Sax/Brit. ☐ Combination  
☐ Jewish-American

8. Religion: ☐ Protestant ☐ Catholic ☐ Jewish ☐ Other  
☐ None
9. How often do you attend religious services, prayer meetings, or study sessions?
- |   |  |
|---|--|
| <input type="checkbox"/> Never                | <input type="checkbox"/> Several times a month |
| <input type="checkbox"/> At most once a year  | <input type="checkbox"/> About weekly          |
| <input type="checkbox"/> Several times a year | <input type="checkbox"/> Several times a week  |
| <input type="checkbox"/> About monthly        | <input type="checkbox"/> Daily                 |

Family and Friends

10. Family size: How many live in your household?   
How many children (under 16)?   
How many older dependents?
11. Excluding your immediate household, how many relatives live nearby?
- |   |
|---|
| <input type="checkbox"/> I have no other relatives at all                   |
| <input type="checkbox"/> I have other relatives, but they are all far away. |
| <input type="checkbox"/> I have one relative nearby.                        |
| <input type="checkbox"/> I have several relatives nearby.                   |
| <input type="checkbox"/> I have many relatives nearby.                      |
12. How often do you see or speak to relatives?
- |   |  |
|---|--|
| <input type="checkbox"/> Never                | <input type="checkbox"/> Several times a month |
| <input type="checkbox"/> At most once a year  | <input type="checkbox"/> About weekly          |
| <input type="checkbox"/> Several times a year | <input type="checkbox"/> Several times a week  |
| <input type="checkbox"/> About monthly        | <input type="checkbox"/> Daily                 |
13. How many of your close friends live nearby?
- |   |
|---|
| <input type="checkbox"/> I have no close friends at all.                  |
| <input type="checkbox"/> I have close friends, but they are all far away. |
| <input type="checkbox"/> I have one close friend nearby.                  |
| <input type="checkbox"/> I have several close friends nearby.             |
| <input type="checkbox"/> I have many close friends nearby.                |
14. How often do you see or speak to your close friends?
- |   |  |
|---|--|
| <input type="checkbox"/> Never                | <input type="checkbox"/> Several times a month |
| <input type="checkbox"/> At most once a year  | <input type="checkbox"/> About weekly          |
| <input type="checkbox"/> Several times a year | <input type="checkbox"/> Several times a week  |
| <input type="checkbox"/> About monthly        | <input type="checkbox"/> Daily                 |
15. Is there one person in whom you can confide, or with whom you can share your feelings?
- ☐ Yes ☐ No ☐ I have more than one such person.
16. How often do you socialize or share leisure activities with friends, spouse or other family?
- |  |   |
|--|---|
| <input type="checkbox"/> Never                 | <input type="checkbox"/> About weekly         |
| <input type="checkbox"/> Monthly or less       | <input type="checkbox"/> Several times a week |
| <input type="checkbox"/> Several times a month | <input type="checkbox"/> Daily                |

17. How often does your spouse accompany you in social and leisure activities?

- ☐ Always
- ☐ Most of the time
- ☐ About half the time
- ☐ Infrequently
- ☐ Never

### Transportation

18. How do you usually get around town?

- ☐ My own personal car
- ☐ Family car
- ☐ Friend's car
- ☐ Taxi
- ☐ Public transportation
- ☐ Walking or bicycling

19. If you use a car, how much of the time do you drive?

- ☐ Always
- ☐ Sometimes
- ☐ Never, but I can drive
- ☐ Never, and I can't drive
- ☐ I never use a car

20. How often is it difficult for you to get around town?

- ☐ Never
- ☐ Infrequently
- ☐ About half the time
- ☐ Most of the time
- ☐ Always

### Financial

21. Family income:      ☐ Less than \$5000      ☐ \$9000-\$11000  
                                 ☐ (annually)      ☐ \$11000-\$13000  
                                 ☐ \$5000-\$7000      ☐ \$13000-\$15000  
                                 ☐ \$7000-\$9000      ☐ More than \$15000

22. Compared to the time before your partner became ill, how is your financial situation?

- ☐ Much worse
- ☐ A little worse
- ☐ About the same
- ☐ A little better
- ☐ Much better



23. Have you had enough money to take care of your own and your family's financial needs during the last two weeks?
- ☐ I had more than enough money.
  - ☐ I had just enough money for needs.
  - ☐ I usually had enough money, with minor problems.
  - ☐ About half the time, I didn't have enough money, but I didn't have to borrow money.
  - ☐ I usually did not have enough money and had to borrow from others.
  - ☐ I had great financial difficulties.

### Your General Health

24. What is your overall state of health at the present time?
- ☐ Excellent
  - ☐ Good
  - ☐ Fair
  - ☐ Poor
25. Since your spouse became ill, how has your health changed?
- ☐ It's gotten much worse.
  - ☐ It's gotten slightly worse.
  - ☐ It's stayed just about the same.
  - ☐ It's gotten slightly better.
  - ☐ It's gotten much better.
26. Since your spouse became ill, have you:
- |                |                              |   |       |
|----------------|------------------------------|---|-------|
| lost weight?   | <input type="checkbox"/> No. | <input type="checkbox"/> Yes, How much? | _____ |
| gained weight? | <input type="checkbox"/> No. | <input type="checkbox"/> Yes, How much? | _____ |

### Your Doctor

27. What is your doctor's specialty?
- ☐ General or Family Practitioner
  - ☐ Internist
  - ☐ Surgeon
  - ☐ Gynecologist
  - ☐ Pediatrician
  - ☐ Psychiatrist
  - ☐ Other \_\_\_\_\_
  - ☐ I don't have a doctor. (Please skip to question #32.)
28. How hard is it for you to travel to this doctor's office?
- ☐ Very hard to get there.
  - ☐ A little hard to get there.
  - ☐ Easy to get there.
29. How hard is it for you to see or speak with this doctor?
- ☐ Always very easy.
  - ☐ Usually very easy.
  - ☐ Usually very hard.
  - ☐ Always very hard.

30. Is this doctor part of the Hospice staff?

☐ Yes.

☐ No.

31. Do you and your spouse have the same doctor?

☐ Yes.

☐ No.

### Your Health Insurance

32. Which of the following does your health insurance cover?

Please check all that apply.

☐ Medical costs while you're a patient in the hospital.

☐ Emergency room services.

☐ Outpatient clinic visits.

☐ Private doctor's office visits.

☐ I don't know.

☐ I have no insurance that covers medical expenses.

### Contact with Hospice Staff

33. How often do you see or telephone the Hospice staff?

☐ Several times a year or less

☐ About weekly

☐ About monthly

☐ Several times a week

☐ Several times a month

☐ Daily

34. How often do you discuss your own personal or health needs with the Hospice staff?

☐ Several times a year or less

☐ About weekly

☐ About monthly

☐ Several times a week

☐ Several times a month

☐ Daily

Contact with Physicians and other Professionals

**DIRECTIONS:** Below is a list of professionals you might contact if you needed assistance. Please make a check mark in the correct space beside each professional.

35. How often have you seen or spoken with each professional about your own personal and health needs, since your spouse became ill?

	I never contact	Contacted only once or twice	Several times a year	About monthly	More than monthly
<u>Your personal or family physician</u>	_____	_____	_____	_____	_____
<u>Another doctor or specialist</u>	_____	_____	_____	_____	_____
<u>Psychiatrist or psychologist</u>	_____	_____	_____	_____	_____
<u>Social worker, nurse, or other health worker</u>	_____	_____	_____	_____	_____
<u>Minister or reli- gious counselor</u>	_____	_____	_____	_____	_____
<u>Other: _____</u>	_____	_____	_____	_____	_____

36. Have you found these professionals to be helpful? (You may check more than one space for each if you need to.)

	Never	Yes, in the past	Yes, recently
<u>Your personal or family physician</u>	_____	_____	_____
<u>Another doctor or specialist</u>	_____	_____	_____
<u>Psychiatrist or psychologist</u>	_____	_____	_____
<u>Social worker, nurse or other health worker</u>	_____	_____	_____
<u>Minister or religious counselor</u>	_____	_____	_____
<u>Other: _____</u>	_____	_____	_____

## RECENT EXPERIENCES QUESTIONNAIRE

DIRECTIONS: Below is a list of events that occur in the lives of many people. Please check any of the events that have happened to you during the past six months.

- 13 You took a vacation.
- 20 You changed residence.
- 45 You retired from your job.
- 47 You got fired.
- 50 You got married.
- 45 You got back together with your spouse after being separated.
- 26 You left school or graduated.
- 63 You spent time in jail.
- 39 You made a major business adjustment.
- 36 You changed to a different line of work.

- 26 Your spouse left work.
- 29 Your son or daughter left home.

You've gotten together with the family:

- 15 much more than before.
- 15 much less than before.

You've argued with your spouse:

- 35 much more than before.
- 35 much less than before.

You've spent much less time than before:

- 19 in leisure activities you enjoy.
- 19 in church or synagogue activities.
- 18 going out with your spouse or friends.

- 44 Someone else in the family was seriously ill (besides your spouse).
- 63 A close family member died.
- 39 Someone new came into your family (through birth or marriage).
- 39 Someone new came to live in your household.

Your living conditions have become:

- 25 much better.
- 25 much worse.

Your working conditions have become:

- 20 much better.
- 20 much worse.

Your work responsibilities have become:

- 29 much greater than before.
- 29 much less than before.

You've had:

- 23 trouble with your boss.
- 29 in-law troubles.
- 28 an outstanding personal achievement.
- 30 a mortgage foreclosure.

You took out a mortgage or loan for:

- 31 more than \$10,000.
- 17 less than \$10,000.

(LCU scoring is added here for purposes of clarification; it does not appear in the questionnaire administered to subjects.)

DIRECTIONS: Below is a list of ways you might have felt or behaved. Please tell me how often you have felt this way DURING THE PAST WEEK by putting a check in the space under the correct number of days for each time.

	RARELY OR NONE OF THE TIME (LESS THAN 1 DAY)	SOME OR A LITTLE OF THE TIME (1-2 DAYS)	OCCASIONALLY OR A MODERATE AMOUNT OF TIME (3-4 DAYS)	MOST OR ALL OF THE TIME (5-7 DAYS)
1. I was bothered by things that usually don't bother me.	_____	_____	_____	_____
2. I did not feel like eating; my appetite was poor.	_____	_____	_____	_____
3. I felt that I could not shake off the blues even with help from my family or friends.	_____	_____	_____	_____
4. I felt that I was just as good as other people.	_____	_____	_____	_____
5. I had trouble keeping my mind on what I was doing	_____	_____	_____	_____
6. I felt depressed.	_____	_____	_____	_____
7. I felt that everything I did was an effort	_____	_____	_____	_____
8. I felt hopeful about the future.	_____	_____	_____	_____
9. I thought my life had been a failure.	_____	_____	_____	_____
10. I felt fearful.	_____	_____	_____	_____
11. My sleep was restless.	_____	_____	_____	_____
12. I was happy.	_____	_____	_____	_____
13. I talked less than usual.	_____	_____	_____	_____
14. I felt lonely.	_____	_____	_____	_____
15. People were unfriendly.	_____	_____	_____	_____
16. I enjoyed life.	_____	_____	_____	_____
17. I had crying spells.	_____	_____	_____	_____
18. I felt sad.	_____	_____	_____	_____
19. I felt that people disliked me.	_____	_____	_____	_____
20. I could not get "going."	_____	_____	_____	_____

DIRECTIONS: Below is a list of problems and complaints that people sometimes have. Please read each one carefully. After you have done so, please place a check mark in one of the spaces to the right that best describes how much that problem has bothered or distressed you IN THE PAST WEEK, INCLUDING TODAY. Make only one check mark for each problem and do not skip any items.

HOW MUCH WERE YOU BOTHERED BY:	Not at all	A little bit	Moderately	Quite a bit	Extremely	HOW MUCH WERE YOU BOTHERED BY:	Not at all	A little bit	Moderately	Quite a bit	Extremely
Example: Backaches?	—	✓	—	—	—	17. Numbness or tingling in parts of your body?	—	—	—	—	—
1. Headaches?	—	—	—	—	—	18. A lump in your throat?	—	—	—	—	—
2. Nervousness or shakiness inside?	—	—	—	—	—	19. Feeling weak in parts of your body?	—	—	—	—	—
3. Faintness or dizziness?	—	—	—	—	—	20. Feeling keyed up or tense?	—	—	—	—	—
4. Feeling easily annoyed or irritated?	—	—	—	—	—	21. Heavy feelings in your arms and legs?	—	—	—	—	—
5. Pains in heart or chest?	—	—	—	—	—	22. Having urges to beat, injure, or harm someone?	—	—	—	—	—
6. Thoughts of ending your life?	—	—	—	—	—	23. Having urges to break or smash something?	—	—	—	—	—
7. Trembling?	—	—	—	—	—	24. Spells of terror or panic?	—	—	—	—	—
8. Suddenly being scared for no reason?	—	—	—	—	—	25. Getting into frequent arguments?	—	—	—	—	—
9. Temper outbursts that you could not control?	—	—	—	—	—	26. Feeling so restless you couldn't sit still?	—	—	—	—	—
10. Pains in lower back?	—	—	—	—	—	27. Feeling that familiar things are strange or unreal?	—	—	—	—	—
11. Feeling fearful?	—	—	—	—	—	28. Shouting or throwing things?	—	—	—	—	—
12. Heart pounding or racing?	—	—	—	—	—	29. Feeling pushed to get things done?	—	—	—	—	—
13. Nausea or upset stomach?	—	—	—	—	—	30. Feelings of guilt?	—	—	—	—	—
14. Soreness of your muscles?	—	—	—	—	—		—	—	—	—	—
15. Trouble getting your breath?	—	—	—	—	—		—	—	—	—	—
16. Hot or cold spells?	—	—	—	—	—		—	—	—	—	—

# HEALTH QUESTIONNAIRE

A. DIRECTIONS: Below is a list of illnesses some adults suffer from. Check whichever of those illnesses you now have. Also, check whether the illnesses started before your spouse became seriously ill or after your spouse became seriously ill.

	I have it now	Started before my spouse became seriously ill	Started after my spouse became seriously ill
1. Diabetes	_____	_____	_____
2. Cancer	_____	_____	_____
3. Anemia	_____	_____	_____
4. Kidney disease	_____	_____	_____
5. High blood pressure	_____	_____	_____
6. Heart trouble	_____	_____	_____
7. Bleeding disorder	_____	_____	_____
8. Asthma/hay fever	_____	_____	_____
9. Epilepsy/seizures	_____	_____	_____
10. Stroke	_____	_____	_____
11. Blindness	_____	_____	_____
12. Thyroid disease	_____	_____	_____
13. Mental illness	_____	_____	_____
14. Stomach or bowel problems	_____	_____	_____
15. Arthritis	_____	_____	_____
16. Other _____	_____	_____	_____
17. Other _____	_____	_____	_____
18. Other _____	_____	_____	_____

B. Please list any other serious illnesses you had in your life. How long ago was the last time each one gave you trouble? Use the list of illnesses in part A. to help you answer.

Illnesses	How long ago was the last time the illness gave you trouble?
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. Other _____	_____
7. Other _____	_____
8. Other _____	_____

C. If you haven't already mentioned them, please list any major operations you've had, and how long ago you had them.

Operation	How long ago?
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. _____	_____
7. _____	_____
8. _____	_____

D. What prescribed medications do you now take? Please list their names. (If you don't know, I can help you identify them.)

1. _____	7. _____
2. _____	8. _____
3. _____	9. _____
4. _____	10. _____
5. _____	11. _____
6. _____	12. _____

E. Do you take any of the following kinds of medicines? Please check whichever ones you have started to take or have increased the amount that you take, since your spouse became ill.

	I now take it.	I've started to take it, or have had to increase the amount that I take, since my spouse became ill.
1. Laxatives	_____	_____
2. Antacids	_____	_____
3. Aspirin/pain pills	_____	_____
4. Sedatives	_____	_____
5. Tranquilizers	_____	_____
6. Sleeping pills	_____	_____
7. Other _____	_____	_____
8. Other _____	_____	_____
9. Other _____	_____	_____
10. Other _____	_____	_____

F. Do you use any of the following substances? Please check whichever ones you have started to use, or have increased the amount that you use, since your spouse became ill.

	I now use it.	I've started to use it, or have increased the amount that I use, since my spouse became ill.
1. Alcoholic beverages	_____	_____
2. Cigarettes	_____	_____
3. Coffee or tea	_____	_____
4. Other _____	_____	_____
5. Other _____	_____	_____



## G. Medical Symptom Checklist

**DIRECTIONS:** This is a list of medical symptoms that people can experience. Some of these may have bothered you at one time or other in your life, while others you may have never experienced at all. Please make a check next to those symptoms which you have started to notice, or which have become definitely worse, since your spouse became seriously ill.

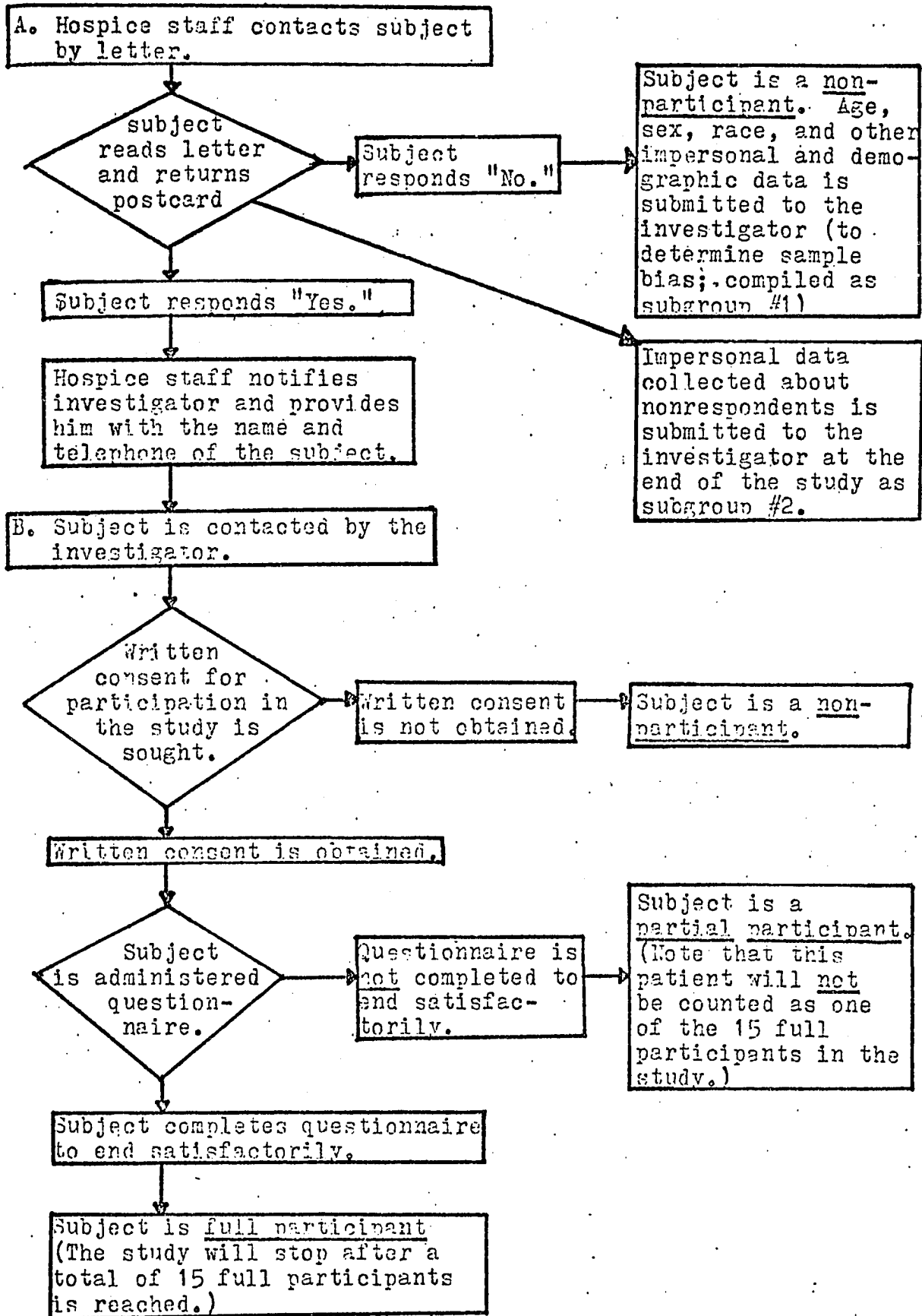
- |  |  |   |
|--|--|---|
| <input type="checkbox"/> Loss of appetite                | <input type="checkbox"/> Pain in chest or heart                    | <input type="checkbox"/> Numbness or tingling of arms and legs          |
| <input type="checkbox"/> Excessive appetite              | <input type="checkbox"/> Wheezing                                  | <input type="checkbox"/> Muscle aches, pains, or cramps                 |
| <input type="checkbox"/> Excessive thirst                | <input type="checkbox"/> Shortness of breath                       | <input type="checkbox"/> Trouble falling asleep                         |
| <input type="checkbox"/> Fevers or chills                | <input type="checkbox"/> Coughing                                  | <input type="checkbox"/> Awakening from sleep too early                 |
| <input type="checkbox"/> Excessive sweating              | <input type="checkbox"/> Swelling of both ankles                   | <input type="checkbox"/> Trouble waking up                              |
| <input type="checkbox"/> General fatigue                 | <input type="checkbox"/> Trouble lying flat in bed without pillows | <input type="checkbox"/> Nightmares                                     |
| <input type="checkbox"/> Heat or cold intolerance        | <input type="checkbox"/> Racing or pounding of the heart           | <input type="checkbox"/> Hearing things or people that aren't there     |
| <input type="checkbox"/> Skin growths                    | <input type="checkbox"/> Varicose veins                            | <input type="checkbox"/> Seeing things or people that aren't there      |
| <input type="checkbox"/> Rash or itch                    | <input type="checkbox"/> Phlebitis                                 | <input type="checkbox"/> Forgetfulness                                  |
| <input type="checkbox"/> Change in hair color or texture | <input type="checkbox"/> Abdominal pain                            | <input type="checkbox"/> Difficulty concentrating                       |
| <input type="checkbox"/> Skin infections or boils        | <input type="checkbox"/> Nausea/upset stomach                      | <input type="checkbox"/> Sluggishness or slowness                       |
| <input type="checkbox"/> Headaches                       | <input type="checkbox"/> Indigestion                               | <input type="checkbox"/> Diminished sex drive                           |
| <input type="checkbox"/> Migraine attacks                | <input type="checkbox"/> Vomiting or retching                      | <input type="checkbox"/> Terror or panic spells                         |
| <input type="checkbox"/> Flushing                        | <input type="checkbox"/> Vomiting of blood                         | <input type="checkbox"/> Irritability                                   |
| <input type="checkbox"/> Pallor                          | <input type="checkbox"/> Diarrhea                                  | <input type="checkbox"/> Raising of hair                                |
| <input type="checkbox"/> Blurred vision                  | <input type="checkbox"/> Constipation                              | <input type="checkbox"/> Giddiness                                      |
| <input type="checkbox"/> Double vision                   | <input type="checkbox"/> Blood in stools                           | <input type="checkbox"/> Carelessness or tendency to get into accidents |
| <input type="checkbox"/> Eye irritation                  | <input type="checkbox"/> Black, tarry stools                       |   |
| <input type="checkbox"/> Diminished hearing              | <input type="checkbox"/> Rectal pain or irritation                 |   |
| <input type="checkbox"/> Ringing in the ears             | <input type="checkbox"/> Pain or burning when passing urine        |   |
| <input type="checkbox"/> Earaches                        | <input type="checkbox"/> Dark brown or bloody urine                |   |
| <input type="checkbox"/> Dizziness                       | <input type="checkbox"/> Excessive urination                       |   |
| <input type="checkbox"/> Nosebleeds                      | <input type="checkbox"/> Need to wake from sleep to urinate        | <b>Men only:</b>  |
| <input type="checkbox"/> Runny nose                      | <input type="checkbox"/> Bone pain                                 | <input type="checkbox"/> Pain or discomfort in testicles                |
| <input type="checkbox"/> Toothaches                      | <input type="checkbox"/> Joint stiffness                           |   |
| <input type="checkbox"/> Facial pain                     | <input type="checkbox"/> Arthritic pain                            | <b>Women only:</b>  |
| <input type="checkbox"/> Bleeding gums                   | <input type="checkbox"/> Backache                                  | <input type="checkbox"/> Irregularity of periods                        |
| <input type="checkbox"/> Mouth sores                     |  | <input type="checkbox"/> Excessive flow                                 |
| <input type="checkbox"/> Dry mouth                       |  | <input type="checkbox"/> Diminished flow                                |
| <input type="checkbox"/> Trouble swallowing              |  | <input type="checkbox"/> Menstrual cramps                               |
| <input type="checkbox"/> Hoarseness or voice change      |  | <input type="checkbox"/> Vaginal discharge                              |
| <input type="checkbox"/> Stiff neck                      |  | <input type="checkbox"/> Vaginal pain or irritation                     |
| <input type="checkbox"/> Swollen glands or lymph nodes   |  |   |
| <input type="checkbox"/> Lumps in breast                 | <input type="checkbox"/> Fainting spells                           |   |
| <input type="checkbox"/> Soreness of breasts             | <input type="checkbox"/> Muscle weakness or paralysis              |   |
| <input type="checkbox"/> Coughing up blood               | <input type="checkbox"/> Tremors or shakiness                      |   |

## DATA SHEET ABOUT YOUR SPOUSE

1. Your spouse's age in years: \_\_\_\_\_
2. Your spouse's occupation:
  - \_\_\_\_ Higher executive, proprietor of large concern, or major professional
  - \_\_\_\_ Business manager, proprietor of medium-sized business, lesser professional, or graduate student
  - \_\_\_\_ Administrative personnel, or proprietor of small, independent business
  - \_\_\_\_ Clerical or sales worker, technician, owner of little business, or undergraduate student
  - \_\_\_\_ Skilled manual employee
  - \_\_\_\_ Machine operator or semi-skilled employee
  - \_\_\_\_ Unskilled employee
  - \_\_\_\_ Unemployed—no previous job skill
  - \_\_\_\_ Housewife/house-husband
3. Your spouse's education:
  - \_\_\_\_ Graduate or professional training
  - \_\_\_\_ Standard college or university graduate
  - \_\_\_\_ Partial college or business college
  - \_\_\_\_ High school graduate
  - \_\_\_\_ Partial high school training
  - \_\_\_\_ Completed 7-9 grades
  - \_\_\_\_ Less than 7 years school
4. Your spouse's employment status:
 

____ never worked	____ unemployed
____ retired	____ part time
	____ full time
5. To the best of your knowledge, what is the illness that your spouse is suffering from now?  
 \_\_\_\_\_
6. Where in his/her body did the disease start? \_\_\_\_\_
7. Where in his/her body is the disease now? \_\_\_\_\_
8. How long has your spouse been sick? \_\_\_\_\_ Years \_\_\_\_\_ Months
9. How long have you known that your spouse's illness is serious?  
 \_\_\_\_\_ Years \_\_\_\_\_ Months
10. What symptoms of the illness or treatment are most troublesome to your spouse? Please list them.  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## Flow of Individual Subjects through Study



## APPENDIX IV

## CODING OF THE QUESTIONNAIRE

(Please refer to the questionnaire)

Coding of forced choice items is done by assigning numerical value to each choice. All items on pages 1-5, each line of question #35, and questions #1-#4 on page 13 are coded in that way. Generally, the content of lower valued choices are less frequent, further away, fewer, worse, or more difficult than higher valued choices. The lowest value of any choice checked is always 1.

Each line of question #36 is coded by assigning a value of 1 for "Never," 2 for "Yes, in the past," and 4 for "Yes, recently." The values of the responses for each line are added to give one score of helpfulness for each type of profession.

Pages 7, 8, and 8 are coded as described above (Section III.A.).

Sections of the Health Survey (pages 10-12) are coded as follows:

Section A: The three blanks in each line are assigned values of 1, 2, and 4 respectively. The total for each line is calculated. In addition, the total number of current illnesses, number of illnesses starting before the spouse became seriously ill, and the number starting after the spouse became seriously ill are each determined.

Sections B and C: The total number of illnesses and

operations is determined.

Section D: The number of medications prescribed is determined.

Sections E and F: For each line, the first blank is assigned a value of 1 and the second a value of 2. These are added to give a score of usage for each type of medication or habitual substance.

Section G: Symptoms are assigned a number and that number recorded for each symptom checked. In addition, the number of symptoms for each bodily region and the total number of symptoms are tallied.

On page 13, question #5 is coded as mild = 1, serious = 2, and terminal = 3. For questions #6 and #7 the bodily region of the place where the disease started or progressed to is coded. The code used corresponds to the code of bodily regions used in the medical symptom checklist on page 12. Questions #8 and #9 are coded in total number of months. The symptoms in question #10 are coded by bodily region and compared with the symptoms experienced by the subject. The matching of any of these symptoms with those elicited from the subject on page 12 suggests the presence of identification phenomena. The matching of bodily region of the responses to questions #6, #7, or #10 with those for the subject's symptoms is also suggestive, although less so.

Several variables are derived:

1. Overall Accessibility to Support (nonprofessional):

This is a measure of closeness or accessibility to

support from family (question #11), friends (question #13), religion (question #8), and confidant(e) (question #15). Each is taken to be an equal measure of social support. Questions #8 and #15 are weighted to bring them to a five-point scale value. The sum of answers to all four questions gives the score of overall accessibility.

2. Overall Utilization of Support (nonprofessional):

This is a measure of utilization or frequency of contact with religious organizations (question #9), family (question #12), friends (question #14), and frequency of social/leisure activities (question #16). The response values of all these are added together to give a total score.

3. Current Socioeconomic Status/Social Class: This is simply the greater of the SES scores and social classes determined for husband and wife.

4. Projected Change in Socioeconomic Status: This is calculated in the following manner: if the subject works or if the couple is retired, the projected change following death of the patient is zero. If the patient is not retired and has the higher rated SES score, then the difference between the SES scores of the patient and subject is the projected change. If the patient is not retired, but has the lesser score, the projected change is zero. This is meant to represent projected loss of social status of the survivor following the death.

5. Overall Outcome Situations: Based on the questionnaire, there are five outcomes of health and professional

help-seeking of interest to this study:

a. Presence of serious medical illness that is untreated medically.

b. Presence of serious medical illness that is untreated at all.

c. Evidence of serious psychiatric disturbance that is untreated psychiatrically.

d. Evidence of serious psychiatric disturbance that is untreated at all.

e. Evidence of serious psychiatric disturbance that is treated medically.

These can be coded yes or no as they pertain to each subject.

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